QUALITY OF LIFE IN PATIENTS WITH DIFFERENTIATED THYROID CARCINOMA IN A SOUTH AFRICAN POPULATION: WHAT DO PATIENTS THINK?

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Declaration

I, Dr Gabriella Chana Lifshitz, declare that this research report is my own, unaided work. It is being submitted for the degree of Master of Medicine (Nuclear Medicine) at the University of the Witwatersrand, Johannesburg. It has not been submitted for any degree or examination at this or any other University.

(Signature of candidate)

19 March 2022, Johannesburg

Master of Medicine (Nuclear Medicine)

ABSTRACT

Background: Quality of life studies have received increasing interest in the last few years, especially amongst oncology patients. Patients with differentiated thyroid cancer usually have a good prognosis. Traditionally treatment outcomes have been solely based on survival time. Diagnosis and treatment have a strong effect on QOL of these patients.

Materials and methods: Patients attending the thyroid cancer clinic were asked to complete a QOL questionnaire with questions rated using a ten-point scale. Data was collected over a period of three months and including 100 participants.

Results: About half the respondents reported no changes to their physical and psychological well-being and self-worth, no distress of illness, during treatment or any social concerns. Females aged 42-52 years of age reported feelings of usefulness, a change in their happiness level, less control over their lives and low self-worth.

Conclusion: Overall the QOL after treatment can be considered good for most patients. Those at risk for poorer QOL outcome are females aged 42-52 years of age and those who have received high doses of RAI (>150mCi). Doctors have a duty to understand and manage the emotional impact of the cancer diagnosis on the patient.

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INTRODUCTION

Thyroid cancer is the most common malignancy of the endocrine system. Genetic and epigenetic alterations are the driving forces of thyroid cancer. At the core of the molecular pathogenesis is the uncontrolled activity of various signalling pathways[1].

The incidence of thyroid carcinoma is on the rise globally[2]. Although there is limited published data regarding developing countries, the United States reported an increase in incidence from 3.6 per 100,000 persons in 1973 to 8.7 per 100,000 in 2002. This represents a 2.4- fold increase, with a predicted projection of an average 5.5% annually[3,4]. In 2011, more than 500 000 people were living with thyroid cancer in the United States. Several factors have played a role in the rise of incidence. This may be attributable to overall better access to health care services and widespread use of imaging studies that incidentally detect thyroid nodules as well as other factors including exposure to ionizing radiation, environmental factors, and genetic factors[5]. It is, however, important to note that although the incidence of thyroid carcinoma is increasing, the case fatality of thyroid carcinoma remains low with the annual number of deaths sitting at roughly 5% of the annual number of newly diagnosed cases[6]. The 5-year survival rate has risen to 97.8%. As many as 70% of cases are diagnosed at an early stage when the cancer is localized[7].

Traditionally, the main outcome measure in oncology patients has been survival, based on tumour control. It has been increasingly recognized, however, that the diagnosis and

management of cancer can have a major effect on every aspect of the Quality of Life ("QOL") for that patient[8]. The aim of cancer treatment, therefore, should not only focus on survival, but to also preserve the QOL[9], and measuring these changes has been of paramount importance[10].

The diagnosis of cancer is frequently frightening and may have psychological consequences that persist even once the cancer has been successfully treated. There is the fear of incurability regardless of predicted outcome. Once previously healthy individuals are told that they have cancer, it is quite common to experience some degree of fear. This may last anywhere from days to months and in some individuals, it can take years before regaining a former sense of confidence in one's health[11]. Although most forms of thyroid cancer have an excellent prognosis, the word cancer and its connotations are frightening to most people, and fear of the unknown and what lies ahead is not uncommon. Usually, patients will identify with one of four types of reactions when hearing a cancer diagnosis: facing the situation, belief of healing, alteration of the mental status and denial[6]. The journey and process of being treated for cancer entails a series of changes, which extend beyond the physical. These include both the mental and psychological ability of the patient, their place in society, personal life and how they view themselves[12].

A common scenario preceding the initial diagnosis is that the patient will present in reasonably good health with no feelings of ill health, and simply have a small thyroid nodule that does not cause any symptoms. Many patients have had their thyroid nodules for years prior to a diagnosis of thyroid cancer, and often have had several previously normal

biopsies, and no symptoms. Therefore, it comes as a great shock to the patient who goes from being a healthy patient to one with a diagnosis of cancer[12].

Despite an abundance of positive reassurance, and significant statistics that suggest a very good to excellent prognosis, and despite being told 'not to worry' by friends, family and medical professionals, most patients are understandably shocked and alarmed and often experience large amounts of anxiety, which at times can be disabling[13]. The uncertainty that lies ahead, coupled with the multiple hospital and physicians' visits, technical terms, strange drugs, surgery, hypothyroidism, radioactive iodine and isolation, and disruption of normal daily activities can be overwhelming. Many patients may not have an excellent support network or may not want to burden loved ones and friends with their real fears and anxieties[13,14].

QOL is defined as the perceptions of an individual regarding his or her position in life in the context of the culture and value systems in which he or she lives and in relation to his or her goals, expectations, standards, and concerns[14]. It reflects what they have accepted and incorporated into the perspective of decisions that they make[14]. QOL in a medical context, refers to a multidimensional concept that encompasses perception of negative and positive aspects of physical, emotional, social, and cognitive functions, which could be affected by the disease or its treatment[8]. The QOL in medicine incorporates physical, mental, and social well- being, as well as the patients' ability to perform ordinary tasks in his/ her daily existence[8]. Over the last decade, there has been a growing interest in QOL studies, especially within the oncological field**[15].** These and similar studies aim to identify-anxiety and depression and use those as quantifiable measurements to assess patients.

Several instruments have been developed to assess QOL in patients with head and neck cancer. Among them, the City of Hope Quality of Life questionnaire is a validated, accurate, and internationally accepted survey instrument. The use of such a questionnaire allows the evaluation of QOL and thus leading to a better understanding of the patient's expectations[14].

Due to its high survival rate and good long-term follow- up, well-differentiated thyroid cancer (WDTC) needs special consideration in this regard. Collaboration and understanding needs to be undertaken to appreciate the emotional impact that a patient undergoes when receiving a cancer diagnosis. The treating physician’s responsibility is to collaborate with the patient to ensure psychosomatic balance and good overall QOL.

In the past 20 years, an increasing number of studies have measured QOL as an end point in the evaluation of the effect of the disease and its treatment on the daily life of the patient[16]. However, there have been relatively few QOL studies looking specifically at patients with thyroid cancer[8]. There is a general lack of data regarding this in developing countries. In view of all of this, and that CMJAH Nuclear Medicine department runs the largest thyroid cancer follow up clinic in South Africa, this study aims to assess the quality of life in patients with WDTC in a South African population. This study will evaluate thyroid cancer patients’ well-being, in so far as it relates to the individual’s own perception of their life (rather than in relation to an objective external assessment thereof).

LITERATURE REVIEW

Thyroid cancers are generally considered slow growing and easily treatable. They are relatively rare (accounting for ~2% of cancers diagnosed yearly[17]). Patients diagnosed with thyroid cancer have an overall good physical prognosis and it is often assumed that their quality of life is comparable to the general population. However, both mental and physical health needs to be addressed when treating cancer patients. Both of these factors are determinants of quality of life.

The thyroid gland:

The thyroid gland is a butterfly-shaped organ which is located in the anterior neck region. It has a left and right lobe with the isthmus (a “connecting bridge”) in the middle. A normal thyroid gland cannot be palpated. Brownish-red in colour, the thyroid is rich with blood vessels. Nerves important for voice quality also pass through the thyroid.

The thyroid secretes three hormones, collectively called thyroid hormones. The main hormone is thyroxine, also called T4. Thyroid hormones act throughout the body, influencing metabolism, growth and development, and body temperature. During infancy and childhood, adequate thyroid hormone is crucial for brain development. The C cells in the thyroid produce calcitonin. This hormone plays a small role in keeping a healthy level of calcium in the body. Four or more tiny parathyroid glands are on the back of the thyroid. These glands make parathyroid hormone which maintains normal levels of calcium[3].

Definition, risk factors and incidence:

Thyroid cancer is when cancer develops in the cells of the thyroid. The progression of thyroid cancer is a process of accumulation of these genetic and epigenetic alterations with corresponding progressive derangements of signalling pathways. This, coupled with secondary molecular alterations, amplify their impacts on thyroid tumorigenesis[1].

Normal thyroid cells grow and divide to form new cells as the body needs them. When normal cells grow old or get damaged, they die, and new cells take their place. Sometimes, this process goes wrong. New cells form when the body does not need them, and old or damaged cells do not die as they should. The build-up of extra cells often forms a mass of tissue called a nodule. Thyroid nodules are very common in the general population and the majority are benign[18]. It is estimated that 3-7% of the world's population have a palpable nodule with ~5% of detected thyroid nodules being malignant.

Newly diagnosed thyroid nodules require evaluation in order to exclude a diagnosis of malignancy. As thyroid cancer does not always have symptoms, it may be hard to detect and diagnose. Often, the possible symptoms are not actually caused by thyroid cancer itself. Instead, these symptoms can be caused by the nodule itself. Other symptoms may include a painless swelling in the front of the neck, swollen lymph nodes, voice changes or difficulty swallowing or breathing[3].

Usually, only nodules measuring >1cm are evaluated unless there are other risk factors that can increase the suspicion for malignancy. Risk factors include: a history of radiation to the

head and neck, a family history of thyroid cancer or hereditary thyroid conditions (e.g., medullary thyroid cancer), suspicious ultrasound findings, lymphadenopathy or the female gender[3].

The female gender has a three-fold increased risk of developing thyroid cancer as compared to their male counterparts[17]. Thyroid cancer can occur at any age however the peak is seen between 40-50 years in females and 60- 70 years of age in males.

According to the National Cancer Registry (2017)[16], the following number of cases of the thyroid gland was histologically diagnosed in South Africa during 2017.

National cancer registry for thyroid cancer in males and females (2017) [1].

Group - Males 2017	Actual No of Cases	Estimated Lifetime Risk	Percentage of All Cancers
All males	188	1:1 035	0,47%
Asian males	13	1:783	1,34%
Black males	48	1:2 555	0,35%
Coloured males	24	1:940	0,51%
White males	103	1:302	0,49%

Group - Females 2017	Actual No of Cases	Estimated Lifetime Risk	Percentage of All Cancers
All females	559	1:506	1,34%
Asian females	41	1:225	3,18%
Black females	205	1:1 035	1,05%
Coloured females	73	1:387	1,56%
White females	240	1:136	1,41%

[1] National Cancer Institute http://www.cancer.gov/cancertopics/pdq/treatment/thyroid/HealthProfessional/page3

Diagnostic work-up:

If the initial workup suggests suspicious sonographic features, a fine- needle aspiration (FNA) should be performed. Definitive diagnosis is made via a histological sample of the gland via a needle biopsy or in some cases a lobectomy[19].

Biopsy results are categorized as nondiagnostic, malignant, suspicious for malignancy (50-75% risk), indeterminate or suspicious for malignancy (20-30% risk), follicular lesion of undetermined significance (5-10% risk) and benign[20].

The American Thyroid Association (ATA) recommends thyroid lobectomy for patients with an indeterminate solitary nodule, and a total thyroidectomy for tumours >4 cm[20]. All cytology which suggests malignancy requires surgical removal either a lobectomy or total thyroidectomy (unless in the case of diffuse metastases).

Thyroid cancer subtypes and staging:

Thyroid cancer is diagnosed histologically via FNA biopsy and is categorized into 4 main subtypes. Papillary thyroid cancer (PTC) is the most frequent histologic subtype of thyroid carcinoma (accounting for ~80% of cases), followed by follicular carcinoma. This is collectively referred to as well- differentiated thyroid carcinoma (WDTC) [6].

PTC is the least aggressive subtype as it tends to grow and metastasize slowly. It is composed of multifocal papillary and follicular elements forming sites of adenocarcinoma[21].

Follicular thyroid cancer (FTC) accounts for ~14% of thyroid cancers. This is more aggressive. It may be associated with iodine-deficiency. Hurtle-cell carcinoma is a subtype of FTC[20,21].

Medullary thyroid cancer represents ~3% of thyroid cancers. It is a cancer of non-thyroid cells which are present in the thyroid gland and is often associated with multiple neo-endocrine neoplasia 2. Anaplastic thyroid cancer accounts for ~2% and is the most dangerous form of thyroid cancer. It metastasises early to surrounding lymph nodes and distant sites[22]. Medullary and anaplastic cancers are referred to as poorly differentiated.

After diagnosis, preoperative staging and imaging is done. This may alter the patient's prognosis and treatment. The American Joint Committee (AJCC) has designated thyroid cancer staging by the Tumour, Node, Metastasis (TNM) classification system. The 8th edition is the most recent and is available on the AJCC website (table 1)[23,24].

Table 1. AJCC 8th edition. TNM Staging Thyroid cancer[2].

TNM definitions (AJCC 8e) for papillary, follicular, poorly differentiated, Hürthle cell, medullary, and anaplastic thyroid carcinomas	
TX	Primary tumor cannot be assessed
T0	No evidence of primary tumor
T1	Tumor ≤ 2 cm in greatest dimension limited to the thyroid
T1a	Tumor ≤ 1 cm in greatest dimension limited to the thyroid
T1b	Tumor > 1 cm but ≤ 2 cm in greatest dimension limited to the thyroid
T2	Tumor > 2 cm but ≤ 4 cm in greatest dimension limited to the thyroid
T3*	Tumor > 4 cm limited to the thyroid or gross extrathyroidal extension invading only strap muscles
T3a*	Tumor > 4 cm limited to the thyroid
T3b*	Gross extrathyroidal extension invading only strap muscles (sternohyoid) from a tumor of any size
T4	Includes gross extrathyroidal extension into major neck structures
T4a	Gross extrathyroidal extension invading subcutaneous soft tissues, larynx, trachea, esophagus, or recurrent laryngeal nerve from a tumor of any size
T4b	Gross extrathyroidal extension invading prevertebral fascia or encasing carotid artery or mediastinal vessels from a tumor of any size
NX	Regional lymph nodes cannot be assessed
N0	No evidence of regional lymph nodes metastasis
N0a*	One or more cytologic or histologically confirmed benign lymph node
N0b*	No radiologic or clinical evidence of locoregional lymph node metastasis
N1*	Metastasis to regional nodes
N1a*	Metastasis to level VI or VII (pretracheal, paratracheal, or prelaryngeal/Delphian, or upper mediastinal) lymph nodes; this can be unilateral or bilateral disease
N1b*	Metastasis to unilateral, bilateral, or contralateral lateral neck lymph nodes (levels I, II, III, IV, or V) or retropharyngeal lymph nodes
M0	No distant metastasis
M1	Distant metastasis
*all categories may be subdivided as solitary tumor (s) and multifocal tumor (m) – the largest tumor determines the classification	

As this staging was developed to predict risk for death- not for recurrence- and does not take into account several independent prognostic variables, the ATA developed a three-level risk stratification for patients (table 2).

[2] National Cancer Institute. Thyroid cancer treatment. Updated July 11 2-14

Table 2. ATA risk stratification thyroid cancer[3].

	ATA	Thyroid Cancer Risk Stratification	SNM
Very low risk		Unifocal or multifocal microcarcinomas (< 1cm)	√
		MACIS score < 6, or TNM score: T1–2, N0, M0	√
		In patients < 45 years old: tumors < 4 cm confined to the thyroid	√
		Excludes tumors with aggressive histology* or vascular invasion	√
Low-risk (all criteria must be met)		**In patients < 45 years old:** MACIS < 6, or TNM score: any T any N, M0	√
		In patients ≥ 45 years old: MACIS < 6, or TNM score: T2, N0, M0	√
	√	No local or distant metastases	√
	√	All macroscopic tumor has been resected	√
	√	There is no tumor invasion of locoregional tissues or structures	√
	√	The tumor does not have aggressive histology* or vascular invasion	√
	√	If ^{131}I is given, there is no ^{131}I uptake outside the thyroid bed on the first post-therapy scan	√
Intermediate/Moderate risk (any criteria)		**In patients < 45 years old:** tumors > 4 cm; macroscopic (> 1cm) N1a or N1b; T1–3, N1b, M0	√
		In patients ≥ 45 years old: T3, N0, M0 or T1–3, N1a, M0	√
		MACIS score > 6	√
		Minimally invasive (microscopic capsular, but not vascular invasion) FTC < 4 cm	√
	√	Tumor with aggressive histology* or vascular invasion	√
	√	Microscopic invasion of tumor into the perithyroidal soft tissues at initial surgery	√
	√	Cervical lymph node metastases, or ^{131}I uptake outside the thyroid bed on the post-therapy scan	
High-risk (any criteria)		**In patients < 45 years old:** T4a–4b, any N, M0, or any T, any N, M1	√
		In patients ≥ 45 years old: any T, N1a–1b, M0, AJCC Stages IVA, IVB, IVC	√
		FTC > 4 cm, or macroscopic invasive FTC	√
	√	Distant metastases	√
	√	Macroscopic tumor invasion	√
	√	Incomplete tumor resection	
	√	Thyroglobulinemia out of proportion to what is seen on the post-therapy scan	

Treatment options:

Current treatment recommendations include surgery (thyroidectomy with possible lymph node dissection), and post-surgical radioactive iodine (RAI) remnant ablation[18], followed by medication (thyroid hormone replacement)[,25]. Molecular-targeted therapies with several tyrosine kinase inhibitors (TKIs) are also available for patients with dedifferentiated thyroid cancer. However, TKI therapy is beyond the scope of this discussion.

[3] National Cancer Institute. Thyroid cancer treatment. Updated July 11 2-14

Standard treatment options vary depending on the type and stage of cancer.

Surgery is the most common treatment for thyroid cancer[26]. This may include either a partial removal of the thyroid gland (lobectomy) or a total thyroidectomy as well as removal of the surrounding lymph nodes. Near-total or total thyroidectomy is recommended for the management of thyroid cancer in which the primary tumour is >1.0-2.0cm. Removing the thyroid gland in its entirety reduces the chance for malignancy in the residual parenchyma. It also allows for a more accurate risk assessment as this is based on size and extracapsular infiltration. Thyroidectomy is also recommended as 5-10% of tumour may reside in the contralateral lobe[27,24].

Radioactive iodine has had an important role in the treatment and management of thyroid cancer, dating back to 1946[28]. It is used in conjunction with surgery to completely ablate the thyroid gland and eradicate possible residual cancer[28].

The radioactive iodine (^{131}I) enters the thyroid gland via the sodium iodide transporters and emits short-wavelength beta rays which leads to acute cell death. When administered the first time after surgery, it is referred to as ablation and with subsequent administrations for residual disease it is known as treatment[29].

WDTC has a 10-year survival rate of 90-95%. With this long-term survival rate, there is a need for long-term surveillance and testing for recurrence[30]. Once the appropriate TSH level is reached (following surgery and withdrawal/ withholding thyroid hormone replacement), the ^{131}I is administered orally as a capsule at the appropriate activity.

Patients are then placed on lifelong thyroid hormone therapy (Levothyroxine), available in a formulation commonly known as eltroxin in our environment. Hormone therapy is a cancer treatment that removes hormones or blocks their action and stops cancer cells from growing. In the treatment of thyroid cancer, drugs may be given to prevent the body from making thyroid stimulating hormone (TSH), a hormone that can stimulate cells containing thyroid cancer to grow or recur. Also, because thyroid cancer treatment kills thyroid cells, the thyroid gland is not able to make enough thyroid hormone.

Emotional well-being and quality of life:

Treatment and follow-up care procedures of thyroid cancer impose great challenges on survivors and could potentially affect their health-related quality of life[31]. In general, as previously mentioned, WDTC has a very good prognosis, and an overall long- term survival rate of more than 90%, with variations among subsets of patients. Early-stage papillary thyroid carcinoma has been reported to have a 20-year case fatality rate of less than 1%[7]. However, as the incidence of thyroid carcinoma is rising and the disease-related mortality rate is low [7,8], the long-term quality of life of survivors is an important consideration. In several recent studies, thyroid cancer survivors have been reported to have impairments in long-term health-related quality of life (QOL), despite cure of disease[8]. The reasons for impaired QOL in thyroid cancer survivors in whom the cancer has been cured are not well-understood and are not related to hormonal (thyroid stimulating hormone) levels[9].

Following diagnosis of thyroid cancer, patients and their treating doctors are most concerned about curing disease and prolonging life. It generally found at this point in the

treatment plan (at first learning of the cancer diagnosis), readily available information is a source of comfort to the patient and their families. Despite the excellent expected 10-year survival rate (~93-97%) some patients are still concerned about future health and may experience problems which undermine their quality of life[8]. Patients will respond well to ongoing access to information such as lifestyle factors which may influence recurrence or dietary modifications[32]. Support in dealing with fears regarding recurrence should be provided as it has been found that patients indicate this aspect is an unmet need. Adequate information on recurrence (percentage chance, signs and symptoms), it found to help to reduce the fear amongst patients. A fear of recurrence is often the most problematic, underacknowledged aspect of thyroid cancer management.

Emotional support is reported as inadequate, with a neglecting of psycho-social issues[33]. It may partly be due to patients' reluctance to indulge the information to the doctor; however, it remains role of the treating doctor to help address emotional concerns[33]. This need will continue to be unmet if neither the doctor nor the patient introduces the topic. It is the responsibility of the treating doctor to care for the emotional well-being of the patient just as much as the physical well-being. Medical appointments should provide access to quality medical information in the form of pamphlets or website links to up-to-date accurate information. By having this accurate knowledge easily available, the emotional stress for the patient will be reduced[32]. Even years after successful treatment, patients will still benefit from up-to-date information on the up-to-date clinical management of their disease[33].

Singer et al. found that at the beginning of a thyroid cancer patient's treatment journey, they will experience more problems than the general population[34]. These are independent of

their age and gender. Patients reported significant problems with both constipation and diarrhoea, insomnia and fatigue and role functioning[34].

Following treatment of thyroid cancer, patients will be placed on long-term levothyroxine replacement. Despite adequate control of thyroid hormones (free-thyroxine and thyroid stimulating hormone), it was found that patients showed a persistent impairment in quality of life[35]. There is no correlation between quality of life and thyroid parameters however it has been noted that there is a correlation between patients with an increased body mass index weight may and a negative QOL[36]. Comparing patients with chronic illnesses, QOL is worse in hypothyroid patients as compared to other chronic illnesses, such as diabetes melltus[37].

Financial difficulties as well as social functioning were both highlighted as affecting quality of life[34]. Lincoln et al[38], found a significant decrease in the quality of life in the elderly population (aged 50 years or older). It was also noted amongst their study group that there was a general increase in morale amongst those patients who returned to work / had secure employment (as opposed to those who did not).

Both patient's needs and preferences for receiving information as well as support related to their disease and management need to be addressed. As there is very little information on quality-of-life studies in a South African population, this study can serve as a guide to physicians for future management. The hope of the study is to goal direct management to include psychosocial and emotional support throughout the cancer management and not just address the physical illness.

Problem statement:

As thyroid cancer is known with a long-term survival rate and excellent prognosis, often psychosocial and emotional needs are not met by the treating physician. Quality of life is therefore affected negatively in patients diagnosed with thyroid cancer.

CHAPTER 2

MATERIALS AND METHODS

Ethics clearance was obtained from the University of the Witwatersrand's Human Research Ethics Committee (HREC), ethics clearance number M200126 (Appendix 1). Permission was obtained from the CEO of Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) for the use of the hospital's patient information (Appendix 2).

2.1 Study design

This study was an observational cross-sectional single institution study which was conducted in the Department of Nuclear Medicine at the Charlotte Maxeke Johannesburg Academic Hospital (CMJAH). The study included patients who are currently being followed up at the weekly thyroid cancer clinic. These patients are those who had undergone thyroid surgery; and received therapeutic doses of radioactive iodine within a 10-year period, from 2009-2019. The patients were required to complete a questionnaire which was based on their experiences of having been diagnosed with WDTC. The questionnaire was offered to the patients in four different languages (English, Afrikaans, seSotho and isiZulu) (Appendices 3-6). By offering the questionnaire in the language the patient is most proficient, this allowed the patient to answer as truthfully as possible and eliminated the need for a third-party translator. The patients were required to sign a consent form in their

chosen language to demonstrate that they were provided with the best possible means to express themselves (Appendices 3-6).

The compilation of the questionnaire ensured that the following aspects were evaluated:

(a) Physical well- being:

Fatigue, appetite changes, pain, heat/cold tolerance, dry skin, hair and voice changes.

(b) Psychological well-being:

Coping with disease, feeling of happiness, being in control of one's life, life satisfaction,-self-worth/ appearance, coping at different time intervals of being diagnosed or treated (initial diagnosis, surgery, scanning, treatment, blood tests).

(c) Social concerns:

Emotional impact on family, availability of support, effects of disease on employment (motivation to work, productivity, quality of work), activities of daily living (chores, leisure), financial burden.

The participant was asked to base their answers on their experiences in the last four weeks. The questions were answered using a ten-point scale (0-10). Every question had a scale for the patient to understand what 0 and 10 represented.

The Questionnaire was adapted from the Quality-of-life questionnaire (thyroid Version) from the City of Hope, National Medical Centre and Beckman Research Institute, California (reproduced and adapted with written permission) (Appendix 7).

2.2 Objectives

The primary objective of this research was to investigate how the experience of being diagnosed and treated for (thyroid) cancer impacts on the patient's QOL. In addition to this, the research set out to compare the QOL between different age groups, gender as well as race as well as risk stratification and if there was a correlation based on the amount of radioactive iodine received.

2.3 Population

The study participants included all patients who had histologically proven WDTC and had undergone surgery and treatment with different activities of radioactive iodine (RAI); [1110MBq-11100MBq (30mCi –300mCi)]. To be included in the study, these patients had all been attending the thyroid cancer clinic for a minimum period of at least 6 months following initial RAI therapy.

The study ran over a period of 12 weeks which translated to 12 thyroid cancer clinics. A total of 106 questionnaires were received, of which 5 were excluded because the patients had received treatment 10 or more years prior, and a single questionnaire being excluded for being incomplete. A total of 100 questionnaires were therefore deemed suitable to be included in the research data.

Inclusion criteria:

- Age > 18 years
- Histologically proven WDTC
- Diagnosed within a period not exceeding 10 years
- Undergone total thyroidectomy[4]
- Treated with RAI

Exclusion criteria:

- Incomplete Questionnaire (less than 5 out of 20 questions completed)[5]

2.4 Data collection

The clinical records of the patients attending the thyroid cancer clinic were reviewed to identify those with WDTC and information such as gender, age and ethnicity as well as all the inclusion criteria were extracted. These clinical records are kept in the Charlotte Maxeke Johannesburg Academic Hospital's department of Nuclear Medicine.

Patients who were eligible to participate in the study were provided with an information sheet inviting them to participate in the study (Appendices 3-6). This information sheet explained the purpose of the study, as well as the advantages and disadvantages of

[4] Removal of the entire thyroid gland

[5] Less than 25% completed renders the questionnaire statistically insignificant

completing the Questionnaire. Those who agreed were asked to sign a consent form (Appendices 3-6) to complete prior to completing the Questionnaire.

The study required that the patient read each question and decide if they agree or disagree with the statement. They were then asked to circle a number indicating the degree to which they agree or disagree with the statement according to the word anchors on each end of the scale.

The scoring was based on a scale from 0-10, where 0= worst outcome, 10= best outcome and 3-6= mild-to-moderate outcome.

2.5 Data analysis and statistics

Data analysis was performed using Microsoft Excel (Microsoft Excel Version 16.12, 2018). Although more well-known statistical packages were available to use, all the analysis presented could be performed using Microsoft Excel

For continuous variables, the descriptive results are presented as medians and range (normal or not normally distributed). Categorical variables are summarised as frequencies and percentages.

Correlation between specific aspects of the groups were measured using pivot table fields. A p-value <0.05 was considered significant.

CHAPTER 3

RESULTS

From July 2020- to September 2020, 106 patients (n=106) from the thyroid cancer clinic were invited to participate in the study by completing the research QOL questionnaire. Of the 106 questionnaires which were completed, 6 had to be excluded from the study results. Five of the patients had all been treated ten or more years prior to the study (which qualified for exclusion as per exclusion criteria) and 1 patient did not sufficiently complete the questionnaire. One hundred questionnaires were available for analysis.

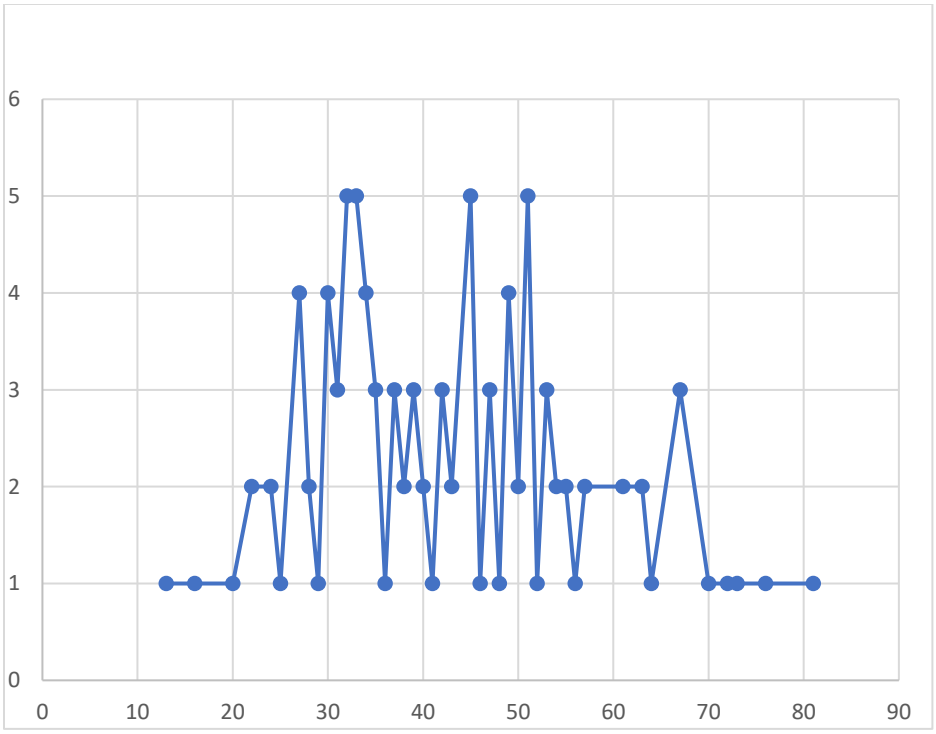
Demographic and medical background variable

Questionnaire respondents (n=100) ranged in age from 18 to 81 years (mean= 42.6 years, standard deviation SD= ±14.0). Most respondents were female (87%; 87/100 female vs 13%; 13/100 male). The majority were black (72%; 72/100), 17% (17/100) were white, 7% (7/100) were mixed race and 4% (4/100) were Asian.

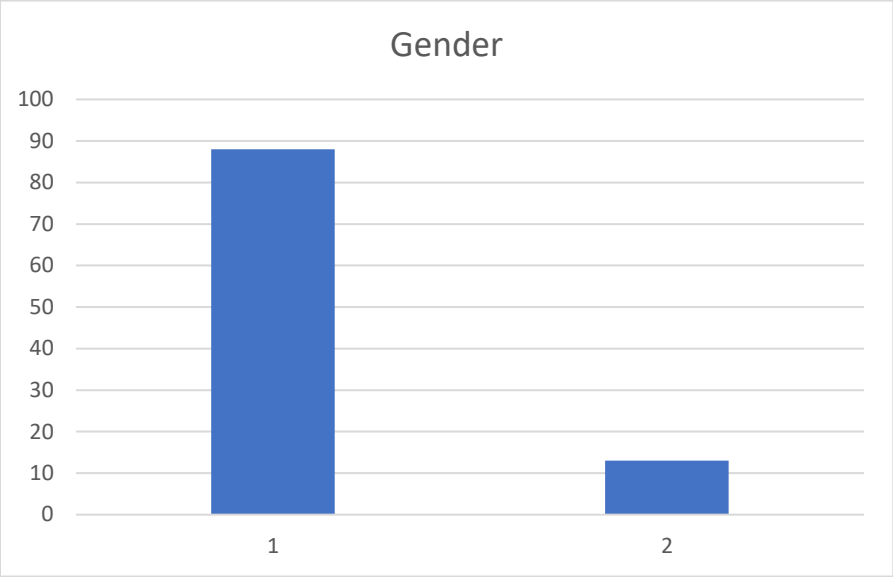
The majority of the respondents 82% (82/100) had been diagnosed with papillary thyroid carcinoma (82%) followed by follicular thyroid carcinoma (17%) (17/100) and 2% (2/100) having hurtle cell carcinoma.

A large majority (85%; 85/100) of respondents had undergone only a total thyroidectomy; 11% (11/100) had undergone a total thyroidectomy with a central lymph node dissection and 5% (5/100) had undergone a total thyroidectomy with a central and lateral lymph node dissection. No respondents reported surgical complications. Of the entire cohort, 52% (52/100) of the patients were risk stratified as low risk, 34% (34/100) intermediate risk and 15% (15/100) high risk.

Graph 1. Age.

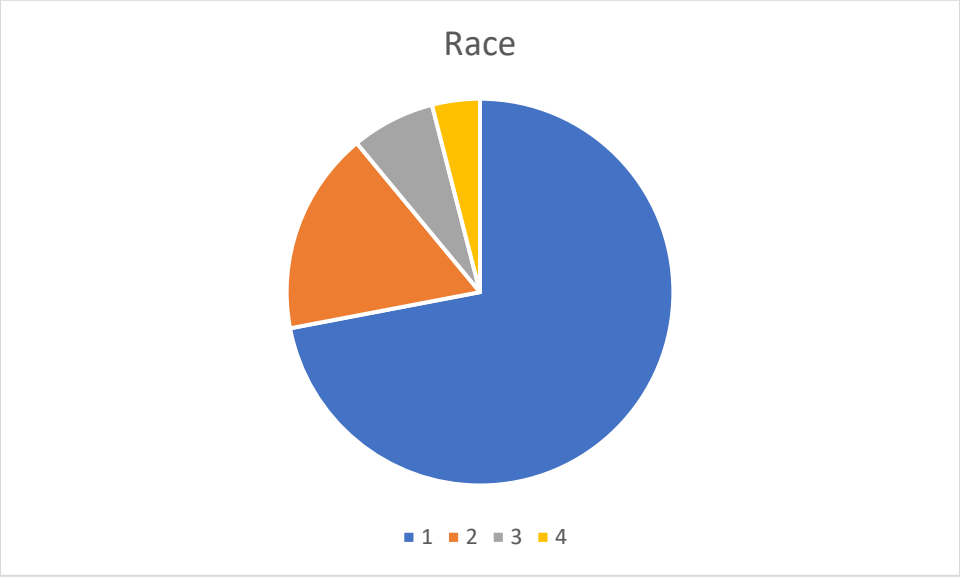


Graph 2. Gender.



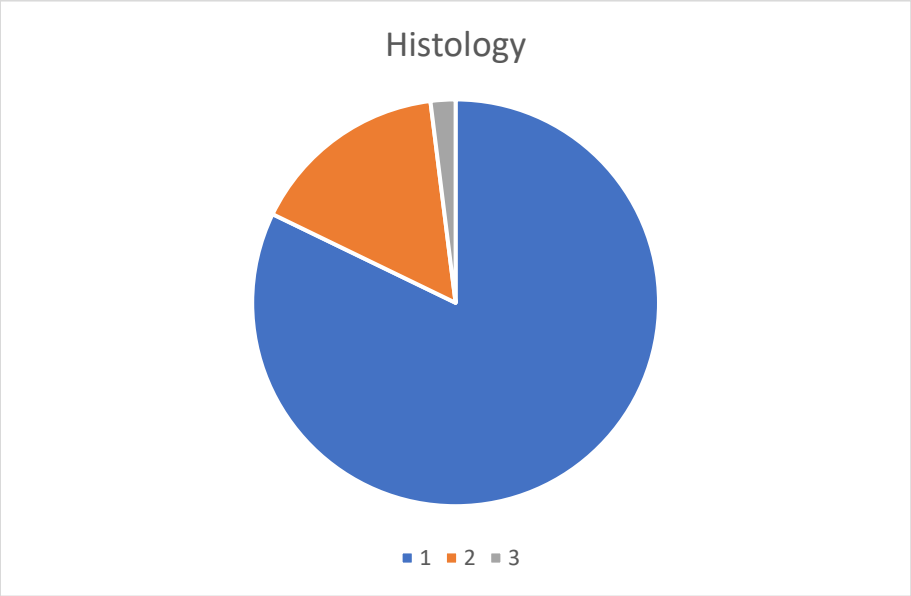
1. Female
2. Male

Graph 3. Race.



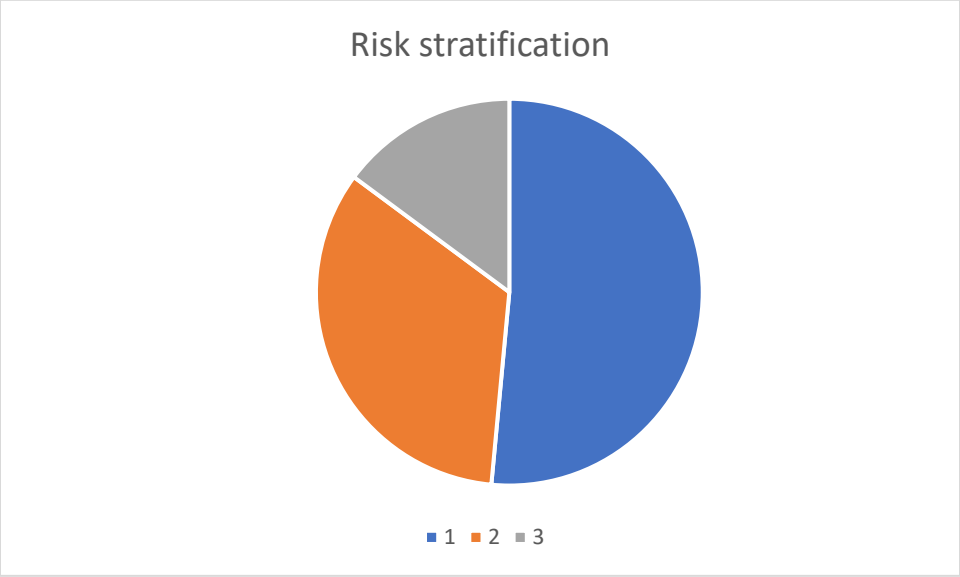
1. Black
2. White
3. Mixed race
4. Asian

Graph 4. Histology.



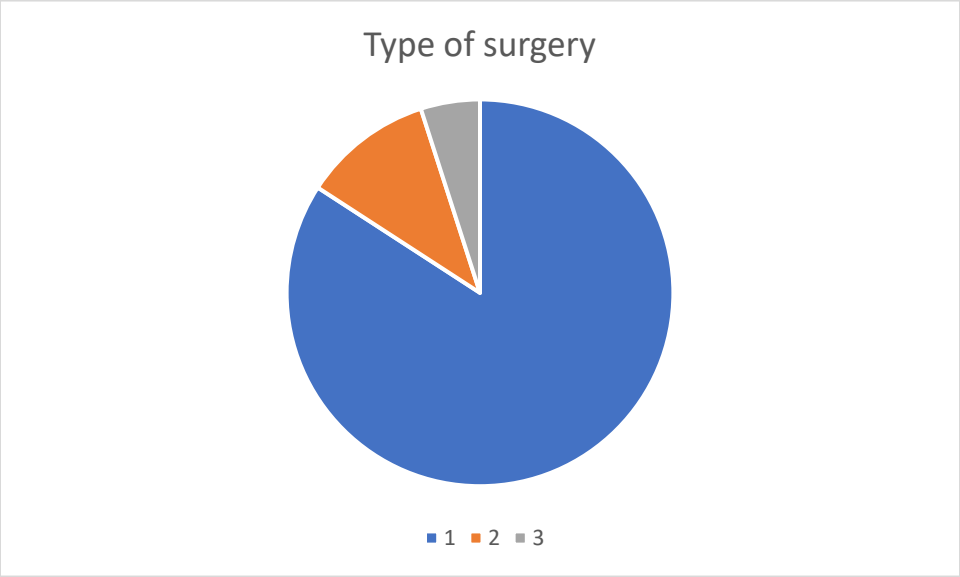
1. Papillary thyroid carcinoma
2. Follicular thyroid carcinoma
3. Hurtle cell

Graph 5. Risk stratification.



1. Low
2. Intermediate
3. High

Graph 6. Type of surgery.



1. Total thyroidectomy
2. Total thyroidectomy and central lymph node dissection
3. Total thyroidectomy and central and lateral lymph

Quality of life Outcomes

Physical well-being

Physical well-being was assessed by looking at symptoms of fatigue, appetite changes, body aches, sleep changes, constipation, heat/cold intolerance, dry skin/ hair changes, voice changes, changes in motor skills, and overall well-being.

Of the 100 respondents, 51 (51%) reported no fatigue and only 8 (8%) reporting extreme fatigue. No appetite changes were reported in 60% (60/100) and 8% (8/100) described extreme changes in their appetite. No body aches noted in half of respondents 50% (50/100) while 12% (12/100) had extreme body aches. No sleep changes were reported in 48% (48/100) of respondents with 12% (12/100) reporting extreme changes. No

constipation noted in 53% of respondents (53/100) with 7% (7/100) suffering from extreme constipation. Just over half (54%; 54/100) of respondents had no changes in their heat and cold tolerance, with 10% (10/100) reporting extreme intolerance to temperature. No changes in skin or hair in 58% (58/100) of respondents; with 10% (10/100) being affected by dry skin and hair changes. No voice changes in 61% (61/100) of respondents with 7% (7/100) reporting a significant voice change. No identifiable motor skill or coordination changes for 81% (81/100) of respondents with a negligible 2% reporting difficulties with their motor ability and coordination.

Amongst the 100 patients reviewed, 21% (21/100) of respondents rated their overall physical health as extremely poor while 25% (25/100) of the interviewed respondents rated their physical health as excellent.

Table 3. Physical well-being.

	No change (rating: 0/10)	Extreme change (rating: 10/10)
Fatigue	51%	8%
Appetite changes	60%	8%
Aches	50%	12%
Sleep changes	48%	12%
Constipation	53%	7%
Heat/Cold intolerance	54%	10%
Dry skin/hair changes	58%	10%
Voice changes	61%	7%
Motor skills	81%	2%
Overall well-being	25%	21%

The data was further broken down into three age categories: namely 0-41 years, 42-52 years and 53-100 years with roughly 33 respondents in each group.

The middle age group experienced 1.5 times (32.33%) more changes to their overall physical well-being than both the younger (15.06%) and the older groups (17.49%).

Comparing males to females, an average score of 21.54% was seen. The females averaged 23.02% compared to the males at 11.54%. Males are 47% less affected than females. However, the male date (as compared to the female) was sparse.

All the individual categories under physical well-being were then summed and the data compared to age and gender.

Once again it was seen that males were generally less affected. Particularly in the age group 42-52 years, there was a 6-fold difference between the males and females.

Average of Overall-wellbeingsum	Column Labels		
Row Labels	0	1	Grand Total
0 - 41	15,34	13,00	15,06
42 - 52	35,86	6,75	32,33
53 - 100	18,03	14,20	17,49
Grand Total	**23,02**	**11,54**	**21,54**
	106,9%	53,6%	

Psychological well-being

Psychological well-being was assessed by looking at ability to cope with diagnosis and treatment, happiness, feeling in control of life and effect on concentration.

No difficulty in coping with diagnosis and treatment for 64% (64/100) of respondents; with only 4% (4/100) finding it extremely difficult.

A great deal of happiness, which was unaffected following diagnosis and treatment, was noted in 22% (22/100) of responders. However, 21% (21/100) described no happiness whatsoever after diagnosis and treatment.

A third (33%; 33/100) of respondents said there are completely in control of their life. A quarter of the patient (25/100) felt they had no control at all of their lives.

A fifth (19%; 19/100) of respondents felt their ability to concentrate or remember things was unaffected. However, 17% (17/100) felt their memory and concentration was extremely poor.

Table 4. Psychological well-being.

	No change (rating: 0/10)	Extreme change (rating: 10/10)
Coping with diagnosis and treatment	64%	4%
Happiness	22%	21%
Feeling in control of life	33%	25%
Concentration	19%	17%

Once again, the data was compared amongst age and gender. Males reported slightly less psychological changes; and this being even less than seen with physical well-being. However, it is important to note, once more in the age category of 42-52 years, a more

substantial difference was noted with males being 17% below the average (however this is smaller than that seen with physical well-being).

Self-worth

Self-worth was assessed by looking at feelings of usefulness, appearance changes and self-concept.

A fifth (21%; 21/100) of respondents felt no use at all to those around them while 35% (35/100) felt an extreme sense of usefulness.

Half (56%; 56/100) of the respondents felt no change in their appearance while 10% (10/100) felt their appearance had changed radically following diagnosis and treatment.

No changes in self-worth following diagnosis and treatment were noted in 61% (61/100) of respondents, while 7% felt an extreme change.

Table 5. Self-worth.

	No change (rating: 0/10)	**Extreme change (rating: 10/10)**
Usefulness	21%	35%
Appearance changes	56%	10%
Self-concept shift	61%	7%

Females in the high-risk category found an above average change in their self-worth (35%). It is relevant to note that the male gender rated higher than their female counterpart with how their self-worth has changed following diagnosis and treatment of thyroid cancer.

Distress of illness and treatment

This was assessed at multiple time points throughout diagnosis and treatment, namely; initial diagnosis, surgery, time since treatment completion, initial treatment/RAI, WBS, blood tests, withdrawal from thyroid hormone, depression, anxiety, fear of future testing, fear of another cancer, fear of thyroid cancer recurrence and fear of metastases.

No distress over the initial diagnosis was described in 42% (42/100) of respondents. 17% (17/100) said they had extreme distress with the initial diagnosis.

No distress with surgery was described amongst 42% (42/100) of respondents. While 21% (21/100) felt extreme distress associated with surgery.

Following treatment completion 58% (58/100) felt no distress with 10% (10/100) feeling extreme distress.

Half (50% 50/100) the respondents interviewed felt no distress at initial treatment and 11% (11/100) felt very distressed.

Half (52%; 52/100) the respondents felt no distress having the whole-body scan. While 11% (11/100) felt huge distress.

No distress was felt while undergoing the required bloodwork for 63% (63/100) of the respondents. While only 8% (8/100) felt immense distress associated with it.

No distress was noted for 58% (58/100) of respondents with having to withdraw from thyroid hormone. However, 14% (14/100) reported immense distress.

No depression or anxiety was reported for 56% (56/100) and 44% (44/100) of respondents. Only 4% (4/100) and 8% (8/100) reported depression and anxiety.

A little more than half of the respondents (52% 52/100) reported no fear of future testing with 12% (12/100) reporting immense fear.

Amongst the respondents, 44% (44/100) reported no fear in a future cancer; 46% (46/100) had no fear of thyroid cancer recurrence and 47% (47/100) had no fear of metastases. 25% (25/100) reported extreme fear of developing another cancer; 21% (21/100) of thyroid cancer recurrence and 23% (23/100) reported an extreme fear of developing metastases.

Table 6. Distress of illness and treatment.

	No change (rating: 0/10)	Extreme change (rating: 10/10)
Initial diagnosis	42%	17%
Surgery	42%	21%
Time since treatment completion	58%	10%
Initial treatment/RAI	50%	11%
Whole body scan	52%	11%
Blood tests	63%	8%
Withdrawal from thyroid hormone	58%	14%
Depression	56%	4%
Anxiety	44%	8%
Fear of future testing	52%	12%
Fear of another cancer	44%	25%
Fear of thyroid cancer recurrence	46%	21%
Fear of metastases	47%	23%

Social concerns

Social concerns were assessed in relation to distress to their family, sufficient support, interference of health and personal relationships, motivation to work, productivity at work, household chores, leisure activities, isolation due to treatment and financial burden.

Of the respondents, 35% (35/100) found the diagnoses of thyroid cancer caused no distress to their family compared to 23% (23/100) who found the diagnosis caused immense distress to their family.

Almost half (46%; 46/100) of respondents reported sufficient support following diagnosis and treatment of thyroid cancer while 26% (26/100) reported insufficient support.

No interference of health and personal relationships were reported amongst 61% (61/100) of the respondents with 6% (6/100) reported no interference of health and personal relationships.

There was no change in motivation to work for 59% (59/100) of respondents however 13% (13/100) however said they were not motivated to work.

Of the respondents, 62% (62/100) reported no change in their productivity at work while 8% (8/100) reported a complete lack of productivity.

Just over half of the respondents (56%; 56/100) reported no change in their ability to complete household chores. However, 9% (9/100) were unable to complete chores.

Just over half of the respondents (58%; 58/100) reported no change in their ability to enjoy leisure activities while 9% reported an inability to enjoy leisure activities.

No isolation due to treatment was reported by 64% (64/100) of respondents yet 8% (8/100) however felt complete isolation due to treatment.

Of the respondents 31% (31/100) felt no financial burden following diagnosis and treatment. A quarter (27% 27/100) of the respondents however felt huge financial strain.

Table 7. Social concerns.

	No change (rating: 0/10)	Extreme change (rating: 10/10)
Distress to your family	35%	23%
Sufficient support	26%	46% (sufficient support)
Interference of health and personal relationships	61%	6%
Motivation to work	59%	13%
Productivity at work	62%	8%
Household chores	56%	9%
Leisure activities	58%	9%
Isolation due to treatment	64%	8%
Financial burden	31%	27%

High risk females were 19% more distressed than their younger contemporizes.

The age group 42-52 years were 2.1 times more socially affected than the other age groups. Females were 1.2 times more affected than their male counterparts (and 1.6 times more concerned than the overall average).

CHAPTER 4

DISCUSSION

Thyroid cancer has a relatively low incidence and often a good prognosis[39]. As the main outcome in oncology patients is curative care and survival, there is a possibility that the emotional aspect is not investigated and is therefore not always managed and addressed by the treating physician[7, 8]. As a result of this, there is scarcity of research on QOL studies. This study set out to address this gap in the research, especially as, to our knowledge, no previous study of this kind has been done in South Africa. The objective of this research was to investigate how the experience of being diagnosed and treated for thyroid cancer impacts on the patient's QOL.

When addressing physical well-being, the following aspects were assessed: symptoms of fatigue, appetite changes, body aches, sleep changes, constipation, heat/cold intolerance, dry skin/ hair changes, voice changes, changes in motor skills, and overall well-being. These parameters may all be affected by the hormonal changes which come when a patient is hypothyroid (following surgery, and withdrawal of endogenous thyroid hormone for preparation for scans).

On average, about half (ranging from 48-81%) of the respondents reported no changes in terms of physical well-being. This included no complaints of fatigue, appetite changes, body

aches, sleep habit changes, constipation, heat/cold intolerance, dry skin or hair changes or voice changes. Very few respondents (~10%) reported extreme changes.

Taking physical well-being into account and looking at the different age categories, it was noted that the respondents aged between 42-52 years of age experienced the most changes to their physical well-being compared to their older and younger counterparts.

Changes relating to physical well-being was also looking at comparing males to females. Males reported fewer physical changes. This was once again noted in the middle age-group. Overall, middle-aged females (42-52 years of age) had the most profound changes to their physical well-being.

The impact of a hypothyroidal state and the related symptoms (fatigue, weakness, weight gain, constipation, and weight gain) can be translated into lower scores regarding quality-of-life[39]. QOL amongst the female responders was poorer than males. Throughout the journey of treatment, females are more affected. The physical aspect of surgery and the impact of a large neck scar has been described as harder to cope with than the actual cancer diagnosis[39].

Psychological well-being was assessed by looking at ability to cope with diagnosis and treatment, happiness, feeling in control of life and any effect on concentration. Respondents found they were able to cope with their diagnosis and treatment. This perhaps is related to the level of counselling given by surgeons and nuclear physicians prior to treatment (surgery and RAI) when explaining the procedure when obtaining consent. A quarter of the

patients expressed they had no happiness and felt they were not in control of their lives. This finding was more profound amongst females than males.

Self-worth was assessed by looking at feelings of usefulness, appearance changes and self-concept. Throughout the respondent group about half reported no changes to how they saw themselves prior to treatment to how they viewed themselves in the present day. One point to note, is that 21% of respondents rated their usefulness prior to diagnosis as compared to the present day as unchanged. However, 35% described their themselves as extremely useless after diagnosis and treatment.

Of significance, females who had high risk thyroid cancer and had received higher activities of radioactive iodine reported more changes to their self-worth. They reported changes to how useful they felt following treatment and diagnosis, along with appearance changes and a shift in their own self-concept.

Changes to QOL based on the RAI dose have previously been reported. Patients receiving high dose (greater than 150mCi) are at risk for poor QOL[39]. It is these patients who need more intensive follow-up, treatment and counselling.

Self-worth was also the only area where the male group scored higher than the female in terms of changes and how they viewed themselves.

Distress of illness and treatment was assessed at different time points of therapy and whether each stage of diagnosis and treatment influenced their mental health. Once again, about half (~50%) of respondents (including both male and female) reported that there was no significant distress caused during diagnosis and treatment.

In terms of social concerns, once again the middle age group came out as being more affected socially.

Gender differences amongst patients' perception of their quality of life were seen throughout this study and this finding is documented in the literature[40,41]. Crevenna et al found that physical functioning, bodily pain, and emotions were affected less in males than in females[40]. This was supported by Giusti et al who reported severely impaired scoring for QOL for females than in males[41].

Limitations to the study included a possible language barrier and level of understanding of how to fill the questionnaire out and circle the appropriate response. The responses may also have been affected by the length of the questionnaire. It is possible that respondents did not answer each question truthfully as they found the procedure cumbersome. The outcome of comparison to male and female may also have been limited by the total number of male respondents to female. Considering the discrepancy in the sizes of the two groups, generalizations become difficult. There was also no baseline QOL score before treatment nor follow-up across time. Evaluation of QOL at different time points and time after treatment could also be another limitation. Underlying health conditions were also not taken into account and this could be another limitation when analyzing responses.

Although the questionnaire was available in four languages, it was long and cumbersome for patients to fill in. Many required assistance in terms of understanding the question posed and knowing how the ten-point score system worked. Future QOL studies may benefit from a shorted, more refined version of the questionnaire with more direct, closed-ended questioning.

The study set out to prove that QOL is negatively impacted in patients who are diagnosed with thyroid cancer, and this is not the case. Throughout all the categories analyzed, most patients noted that in general their quality-of-life has not been affected by the diagnosis, treatment, and management of their thyroid cancer.

In summary, the overall outcome and response of the respondents that emerged from this study was a positive one. The female gender overall reported more changes to their quality-of-life, especially those aged between 42-52 years of age. Patients who receive high dose (greater than 150mCi) need more intensive counselling and follow-up. Overall, however, respondents reported a high quality-of-life.

CONCLUSION

There has been growing interest in the recent years for QOL studies in the oncological field. Patients with differentiated thyroid cancer have a good prognosis with a long-term survival. Despite the excellent prognosis of patients with thyroid cancer, special consideration to quality of life should still be considered.

Overall, the QOL after treatment can be considered good for most patients. The affected parameters included: feeling of uselessness, a change in happiness levels, feeling no longer in control of life and changes to self-worth. Those at risk for poorer QOL outcome are females aged 42-52 years of age and those who have received high doses of RAI (based on their risk category, >150mCi).

Medical professionals have a duty to understand the emotional impact of the cancer diagnosis on the patient and it is their responsibility to work together with the patient to restore and maintain the psychosomatic balance and ensure excellent quality of life.

APPENDICES

APPENDIX 1

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Dr Gabriella Fine Lifshitz

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M200126

NAME: (Principal Investigator)	Dr Gabriella Lifshitz
DEPARTMENT:	Nuclear Medicine and Molecular Imaging Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Quality of life in patients with differentiated thyroid carcinoma in a South African population. What do patients think?
DATE CONSIDERED:	31/01/2020
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr O. Mbakaza and Prof MW. Vangu
APPROVED BY:	CB Penny Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	22/06/2020

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions.Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. I **agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **January** and will therefore be due in the month of **January** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 2

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. N. Mzila
Office of the Clinical Director
Email: Nolwazi.Mzila@gauteng.gov.za
Tell: (011): 488-4812
10 December 2019

Dear Dr. Gabriella Chana Lifshitz

STUDY TITLE: Quality of Life in Patients with Differentiated Thyroid Carcinoma in a South African Population: What do Patients Think?

Permission to review patient file for conduction of the above mentioned study is provisional approved. Your study can only commence once Ethics approval is obtained. Please forward a copy of your Ethics Clearance Certificate as soon as the study is approved by the Ethics Committee for the CEO's office to give you the final approval to conduct the study.

Supported / ~~not supported~~

Dr. M.I. Mofokeng
Clinical Director
DATE: 10/12/2019

Approved / not approved

Ms. G. Bogoshi
Chief Executive Officer
DATE: 12.12.2019

APPENDIX 3

Quality of Life Scale/THYROID

Directions: We are interested in knowing how your experience of having thyroid cancer affects your Quality of Life.
Please answer all of the following questions based on how you have been feeling during the **past four weeks.**

Physical Well Being

1. To what extent have the following been a problem during your illness and treatment:

a) Fatigue

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

b) Appetite changes

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

c) Aches or pain

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

d) Sleep changes

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

e) Constipation

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

f) Tolerance to cold or heat

no problem	0	1	2	3	4	5	6	7	8	9	10	**severe problem**

g) Dry skin or hair changes

no	0	1	2	3	4	5	6	7	8	9	10	**severe**

problem **problem**

h) Voice changes

No problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

i) Motor skills/coordination

No problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

2. Rate your overall physical health:

Extremel poor 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Psychological Well Being Items

3. How difficult is it for you to cope with your disease and treatment?

not at all difficult 0 1 2 3 4 5 6 7 8 9 10 **very difficult**

4. How much happiness do you feel?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

5. Do you feel like you are in control of things in your life?

none at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

6. How is your present ability to concentrate or to remember things?

extremely poor 0 1 2 3 4 5 6 7 8 9 10 **extremely**

7. How useful do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

8. Has your illness or treatment caused changes in your appearance?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

9. Has your illness caused changes in your self-concept (the way you see yourself)?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

10. How distressing were the following aspects of your illness and treatment:

a) Initial diagnosis

not at all 0 1 2 3 4 5 6 7 8 9 10 **very**
distressing **distressing**

b) Surgeries

not at all 0 1 2 3 4 5 6 7 8 9 10 **very**
distressing **distressing**

c) Time since my treatment was completed

not at all 0 1 2 3 4 5 6 7 8 9 10 **very**
distressing **distressing**

d) Initial radioiodine ablation/treatment

not at all 0 1 2 3 4 5 6 7 8 9 10 **very**
distressing **distressing**

e) Whole body scanning

not at all 0 1 2 3 4 5 6 7 8 9 10 **very**
distressing **distressing**

f) "Blood tests" (Thyroid function and Thyroglobulin tests)

not at all 0 1 2 3 4 5 6 7 8 9 10 **very**
distressing **distressing**

g) Withdrawal from thyroid hormone (prior to receiving capsule)

not at all 0 1 2 3 4 5 6 7 8 9 10 **very**
distressing **distressing**

11. How much depression do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

12. How much anxiety do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

13. To what extent are you fearful of:

a) Future diagnostic tests

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

b) Another type of cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

c) Recurrence of your thyroid cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

d) Spreading (metastasis) of your cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

Social Concerns

14. How distressing has your illness been for your family?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

15. Is the amount of support you receive fromothers sufficient to meet your needs?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

16. Is your continuing health care interfering with your personal relationships?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

17. To what degree has your illness and treatment interfered with your employment?

a) Motivation to work

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

b) Productivity at work

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

18. To what degree has your illness and treatment interfered with your activities at home?

a) Household chores

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

b) Leisure activities

no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

19. How much isolation do you feel is caused by your illness and treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

20. How much financial burden have you incurred as a result of your illness and treatment?

none0 1 2 3 4 5 6 7 8 9 10 **a great deal**

******************************The end of questionnaire********************************

Adapted from:

City of Hope

NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH

Quality of Life - THYROID VERSION

Participant Information Sheet

1. Research Project Title

Quality of life in patients with differentiated thyroid carcinoma in Johannesburg, South Africa: What do patients think?

2. Invitation

My name is Dr Gabriella Lifshitz and I am a registrar in the Department of Nuclear Medicine.

You are being invited to take part in this research project. Before you decide to do so, it is important you understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

3. What is the research's purpose?

This research aims to investigate how your experience of having thyroid cancer impacts on your general well-being. This project builds on similar research previously and currently carried out by investigators in other parts of the world and has been designed to allow comparisons with previous findings.

4. Why have I been chosen?

You have been chosen because you were diagnosed with thyroid cancer and have continued your treatment with us in this department.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be able to keep a copy of this information sheet and you should indicate your agreement. You can still withdraw at any time. You do not have to give a reason.

6. What will happen to me if I take part?

You will be asked to complete a paper-based questionnaire which we estimate will take you 10- 15 minutes. Information from your medical file will also be used in the research. There will be no cost to you by participating in this research.

7. What will happen to me if I do not take part?

Your treatment will not be affected and your decision will not influence your future care and continued treatment in our department.

8. What do I have to do?

Please answer the questions in the questionnaire. There are no other commitments or lifestyle restrictions associated with participating.

9. What are the possible disadvantages and risks of taking part?

Participating in the research is not anticipated to cause you any disadvantages or discomfort.

10. What are the possible benefits of taking part?

While there are no immediate benefits for those people participating in the research, it is hoped that this work will have a beneficial impact on how to improve care for our patients with thyroid cancer and ultimately improve their quality of life.

11. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified or identifiable in any reports or publications.

Data collected may be shared in an anonymized form to allow reuse by the research team and other third parties. These anonymized data will not allow any individuals to be identified or identifiable.

12. Will I be recorded, and how will the recorded media be used?

You will not be recorded in any way other than your input to the questionnaire.

13. What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?

The questionnaire will ask about your opinions and feelings since the time you were diagnosed with thyroid cancer. Your views and experience are just what the study is interested in exploring.

14. What will happen to the results of the research project?

Results of the research will be published. You will not be identified in any report or publication. If you wish to be given a copy of any reports resulting from the research, please indicate and we will put you on our list. The result of this study may be submitted to the Human Research Ethics Committee (HREC) at their request.

15. Who is organizing and funding the research?

The research is being conducted by the Department of Nuclear Medicine, University of the Witwatersrand, Johannesburg. It does not require external funding.

16. Who has ethically reviewed the project?

This project has been ethically approved by the Human Research Ethics Committee ([HREC] (medical), University of the Witwatersrand, Johannesburg. Please contact Zanele Ndlovu (Zanele.Ndlovu@wits.ac.za) should you have any queries in this regard.

17. What happens if taking part in the research causes you distress?

We have procured that Alexa Young, a clinical psychologist, will be available to discuss with you any distress you suffer in relation to the research and counsel you on how to resolve such distress.

18. Contacts for further information

Prof MDTH Vangu

Department of Nuclear Medicine, Charlotte Maxeke Johannesburg Academic Hospital & University of the Witwatersrand, Johannesburg, South Africa.

Tel: +27 (0)11 488 3500

email: mboyo-di-tamba.vangu@wits.ac.za

Dr. GC Lifshitz

Department of Nuclear Medicine, Charlotte Maxeke Johannesburg Academic Hospital & University of the Witwatersrand, Johannesburg, South Africa. Tel: Tel: +27 (0)11 488 3560

email: drgabifine@gmail.com

Thank you for taking part in this research.

Written Consent Form

TITLE OF STUDY
Quality of life in patients with differentiated thyroid carcinoma in Johannesburg, South Africa: What do patients think?

I have read and understood the participation information sheet provided.

I have had the opportunity to ask questions and to consider the answers given to me.

I understand that participation in this study is voluntary, that I may decline my consent and if I choose not to participate my decision will not affect my care and future visits at the hospital.

"I _____, consent to participate in the research of Quality of life in patients with differentiated thyroid carcinoma conducted by the Department of Nuclear Medicine, University of the Witwatersrand. Johannesburg.
I have understood the nature of this study and wish to participate.
My signature below indicates my consent.

Signature _____ **Date** _____
Participant

Signature _____ **Date** _____
For principal Investigator

APPENDIX 4

Kwaliteit lewe evaluasie / SKLIDKLIER

Aangepas vanaf

City of Hope

NATIONAL MEDICAL CENTER AND BECKMAN RESEARCH

Agtergrond: Ons stel belang om te weet hoe u ervaring met skildklier kanker die kwaliteit van u lewe beïnvloed.

Antwoord asb die volgende vrae, gebaseer op hoe u gevoel het oor die afgelope vier weke.

Fisiese gesondheid

21. Tot watter mate was die volgende 'n probleem gedurende u siekte en behandeling:

a) Moegheid

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

b) Verandering in eetlus

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

c) Pyn

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

d) Verandering in slaap

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

e) Hardlywigheid

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

f) Aanpassing tot hitte of koue

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

g) Droë vel of verandering in kondisie van hare

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

h) Stem veranderinge

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

i) Motorvaardigheid / koördinasie

geen probleem 0 1 2 3 4 5 6 7 8 9 10 **erg**

22. Algemene fisiese gesondheid:

baie sleg 0 1 2 3 4 5 6 7 8 9 10 **uitsteken**

Emosionele gesondheid

23. Hoe moeilik is dit om u toestand en behandeling te hanteer?

glad nie moeilik 0 1 2 3 4 5 6 7 8 9 10 **baie moeilik**

24. Hoe gelukkig voel u?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

25. Voel u in beheer van dinge in u lewe?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **totaal**

26. Hoe is u huidige vermoë om te konsentreer en dinge te onthou?

uiters swak 01 2 3 4 5 6 7 8 9 10 **baie goed**

27. Hoe onmisbaar (nuttig) voel u?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

28. Het u toestand en behandeling enige veranderinge in u voorkoms veroorsaak?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

29. Het u toestand u selfbeeld geaffekteer?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

30. Hoe angswekkend was die volgende aspekte van u toestand en behandeling:

a) Aanvanklike diagnose

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

b) Sjirurgie

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

c) Tydperk totdat behandeling voltooi is

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

d) Aanvanklike radioaktiewe jodium behandeling

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

e) Radioaktiewe jodium "scan"

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

f) "Bloed toetse" (Skildklier funksie en kanker merkers)

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

g) Tydperk af van die skildklier hormoon behandeline (voor die jodium kapsule)

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

31. Hoe neerslagtig voel u?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

32. Hoeveel angs ervaar u?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

33. Tot watter mate voel u bang vir:

a) Toekomstige toetse

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

b) Ander tipe kanker

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

c) Terugkeer van u skildklier kanker

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

d) Verspreiding van u kanker

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

Sosiale bekommernisse

34. Hoe ontstellend is u toestand vir u familie?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

35. Is die hoeveelheid ondersteuning wat u van ander ontvang genoeg vir u behoeftes?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

36. Meng u aangaande gesondheidsorg in met u persoonlike verhoudings?

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

37. Tot watter mate het u toestand en behandeling ingemeng met u werk?

a) Motivering om te werk

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

b) Produktiviteit by die work

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

38. Tot watter mate het u toestand en behandeling ingemeng met u aktiwiteite tuis?

a) Huishoudelike take

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

b) Ontspanningsaktiwiteite

glad nie 0 1 2 3 4 5 6 7 8 9 10 **baie**

39. Hoeveel isolasie voel u is veroorsaak deur u toestand en behandeling?

geen 0 1 2 3 4 5 6 7 8 9 10 **baie**

40. Hoeveel finansiele las het u ervaar weens u toestand en behandeling?

geen 0 1 2 3 4 5 6 7 8 9 10 **baie**

********** **Einde van die vraelys** **********

Deelnemer inligtingsblad

Titel van navorsingsprojek

Quality of life in patients with differentiated thyroid carcinoma in Johannesburg, South Africa: What do patients think?

Lewenskwaliteit in pasiënte met gedifferentieerde skildklier kanker in Johannesburg, Suid Afrika: Wat dink pasiënte?

Uitnodiging

My naam is Dr Gabriella Lifshitz en ek is ‘n kliniese assistant in die Departement van Kerngeneeskunde.

Ek nooi u om deel te neem aan hierdie navorsingsprojek. Dit is egter belangrik dat u verstaan hoekom die navorsing gedoen word en wat dit behels voordat u instem.

Lees asseblief die volgende inligting deurdagtig en bespreek dit met ander as u wil. Vra ons indien enigiets onduidelik is, of as u addisionele inligting wil hê. Neem u tyd om te besluit of u wil deelneem of nie. Baie dankie dat u die tyd neem om hierdie inligtingsblad te lees.

1) Wat is die doel van hierdie navorsing?

Hierdie navorsing beoog om te bepaal hoe u ervaring met skildklier kanker u algemene welstand beïnvloed. Die projek is gebaseer op soortgelyke navorsing wat in ander dele van die wêreld gedoen is / was en is ontwerp om vergelykings te tref met vorige bevindinge.

2) Hoekom is ek gekies?

U is gekies omdat u gediagnoseer is met skildklierkanker en voortgaan met u behandeling by ons in hierdie departement.

3) Moet ek deelneem?

Die besluit rus by u om deel te neem of nie. Indien u besluit om deel te neem, kan u ‘n kopie van hierdie inligtingstuk hou en u sal u goedkeuring moet aandui. U kan egter enige tyd onttrek sonder om ‘n rede te verskaf.

4) Wat sal met my gebeur indien ek deelneem?

U sal gevra word om a vraelys op papier in te vul, wat om en by 10-15 minute sal neem. [Inligting van u mediese leêr sal ook gebruik word vir die navorsing.] Daar is geen koste om aan hierdie projek deel te neem nie.

5) Wat sal met my gebeur indien ek deelneem?

U behandeling sal nie geaffekteer word nie en u besluit sal nie u toekomstige behandeling en sorg in ons departement beïnvloed nie.

6) Wat moet ek doen?

Antwoord asseblief die vrae in die vraelys. Daar is geen ander verpligtinge of beperkings geassosieer met deelname nie.

7) Wat is die moontlike nadele en risikos met deelname?

Geen nadele, ongemak of risikos word verwag met deelname aan die projek nie.

8) Wat is die potensiële voordele om deel te neem aan hierdie projek?

Daar is geen onmiddellike voordele vir die wat deelneem aan die projek nie. Die hoop is egter dat hierdie navorsingsprojek ‘n positiewe impak sal hê en ons versorging van skildklierkankerpasiënte sal verbeter om uiteindelik hulle kwaliteit lewe te verbeter.

9) Sal my deelname aan hierdie projek konfidensieel gehou word?

Al die inligting wat ons oor u versamel gedurende die loop van hierdie projek sal streng konfidensieel gehou word. Dit sal nie moontlik wees om u te identifiseer nie en u identiteit sal nie ontbloot word in enige verslae of publikasies nie. Versamelde data mag gedeel word in ‘n anonieme format om weer gebruik te word deur die navorsingspan en ander onafhanklike partye. Die anonieme data sal nie enige individue kan identifiseer nie.

10) Sal daar ‘n stem opname wees en hoe sal dit gebruik word?

U sal nie opgeneem word nie.

11) Watter inligting word van my vereis en hoekom is die insameling van hierdie inligting nodig om die projek se doel te bereik?

Die vraelys behels vrae oor u opinie en gevoelens sedert u skildklier kanker. U opinies en ervaring is presies wat hierdie studie wil ondersoek.

12) Wat gebeur met die resultate van die projek?

Navorsingsresultate sal gepubliseer word in wetenskaplike joernale. U sal nie geïdentifiseer word in enige verslag of publikasie nie. Dui asb op die vraelys aan ndien u ‘n kopie van enige van die resultate wil hê, dan sal ons u op ons lys plaas. Die resultate mag aan die “Human Research Ethics Committee” (HREC) verskaf word indien hulle dit aanvra.

13) Wie organiseer en befonds hierdie navorsing?

Hierdie navorsing word gedoen deur die Departement van Kerngeneeskunde, Universiteit van die Witwatersrand, Johannesburg. Eksterne befondsing word nie benodig nie.

14) Wie het die etiese aspekte van die projek nagegaan?

Die projek is eties goedgekeur deur die “Human Research Ethics Committee” ([HREC] (medical), van die Universiteit van die Witwatersrand, Johannesburg. [Kontak asseblief vir Zanele Ndlovu (Zanele.Ndlovu@wits.ac.za) indien u enige navrae het in hierdie verband.]

[

15) Wat gebeur as u deelname in die navorsing u spanning veroorsaak?

Alexa Young, ‘n kliniese sielkundige, is beskikbaar om enige spanning wat u moontlik ervaar in verband met die navorsing te bespreek asook berading aan te bied om die spanning op te los.]

16) Kontak besonderhede vir verdere inligting:

Prof MDTH Vangu, Departement van Kerngeneeskunde, Charlotte Maxeke Johannesburg Akademiese Hospitaal & Universiteit van die Witwatersrand, Johannesburg, Suid Afrika.

Tel: +27 (0)11 488 3500, email: mboyo-di-tamba.vangu@wits.ac.za

Dr. GC Lifshitz, Departement van Kerngeneeskunde, Charlotte Maxeke Johannesburg Akademiese Hospitaal & Universiteit van die Witwatersrand, Johannesburg, Suid Afrika.

Tel: +27 (0)11 488 3560, email: drgabifine@gmail.com

Dankie dat u deel neem aan hierdie navorsingsprojek.

Geskrewe instemming

Titel van navorsingsprojek

Quality of life in patients with differentiated thyroid carcinoma in Johannesburg, South Africa: What do patients think?

Lewenskwaliteit in pasiënte met gedifferentieerde skildklier kanker in Johannesburg, Suid Afrika: Wat dink pasiënte?

Ek het die deelnemer inligtingsblad gelees en verstaan.

Ek het die geleentheid gehad om vrae te vra en oor die antwoorde te dink.

Ek verstaan dat deelname aan hierdie studie vrywillig is en dat ek my toestemming mag onttrek indien ek nie verder wil deelneem nie. My ontrekking sal nie my sorg en toekomstige behandeling by hierdie hospital beïnvloed nie.

"Ek _____, stem in om deel te neem aan die navorsingsprojek oor Lewenskwaliteit in pasiënte met gedifferentieerde skildklier kanker in die Departement van Kerngeneeskunde, Charlotte Maxeke Johannesburg Akademiese Hospitaal & Universiteit van die Witwatersrand.

Ek verstaan waaroor hierdie studie gaan en wil graag deelneem.

My handtekening bevestig my toestemming.

Handtekening _____ **Datum** _____
Deelnemer

Handtekening _____ **Datum** _____
Hoof Ondersoeker

APPENDIX 5

Sehlomathiso sa pele

Tekanyo ea boleng ba bophelo

Tlhaloso: Re lakatsa ho tseba ka liketsahalo tsa bophelo ba hao kamanong le kankere ea thyroid.

Re kopa hore o arabe lipotso tse latelang ho hlalosa hore o ikutloa joang libekeng tse nne tse fetileng.

Boemo ba mmele

1. Hlalosa boholo ba mathata a hao nakong ea bokulo le pheko

    a. Mokhathala

        Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

    b. Phetoho ea takatso ea lijo

        Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

    c. Mahlaba

        Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

    d. Liphetoho borokong

        Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

    e. Ho sokela/pipitleloa

        Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

    f. Mamello e mohatsela kapa mocheso

Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

g. Komello ea letlalo kapa liphetoho moriring

Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

h. Liphetoho tsa lentsoe

Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

i. Tsepamo/ cordination

Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

2. Bophelo ba hao ka kakaretso

Extremely poor 0 1 2 3 4 5 6 7 8 9 10 bo ntlafetse haholo

Boemo ba boleng ba kelello

3. Ho boima hakae ho phela ka lefu lee le ho fumana pheko. Tsela ee e boima hakae how wena?

Haho boima 0 1 2 3 4 5 6 7 8 9 10 ho boima haholo

4. O thabile ha ka kang?

Ha kea thaba 0 1 2 3 4 5 6 7 8 9 10 ke thabile haholo

5. E be o ikutloa o laola bophelo ba hao?

Ha ke bo laole 0 1 2 3 4 5 6 7 8 9 10 ke na le taolo e felletseng

6. Ha joale khopolo ea hao e eme joang?

E mpe haholo 0 1 2 3 4 5 6 7 8 9 10 Hantle haholo

7. O ikutloa o na le molemo na?

Che, ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

8. E be ho kula ha hao ho fetotse chebahalo ea hao?

Che, ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

9. E be ho kula ha hao ho fetotse tsela eo o iponang ka teng?

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

10. Ho kula le phekolo ea hao li o tetebetsa ha kae?

a. Qalong ea bokuli?

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

b. Ho buuoa

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

c. A o tetebetse ka mora qeto ea phekolo

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

d. A o tetebetse ka mora hore o utloe tsela eo o tlo thusoa ka eona?

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

e. E be ho hloloa hoa mmele ohle wa hao hoa tetebetsa?

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

f. E be ho etsa liteko tsa mali tsa thyroid lia o tetebetsa?

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

g. E be ho se noe lipilisi tsa li-hormone tsa thyroid ha ho u tetebetse

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

11. O hatellehile maikutlong ha kae

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

12. O tshwenyehile ha kae/ o khathatsehile hakae moeng?

Che ho hang 0 1 2 3 4 5 6 7 8 9 10 E, haholo

13. Tekanyo ea ho tshoha ha hao mabapi le tse latelang:

a. Liteko tse sa tla etsoa?

Ha ke tshabe 0 1 2 3 4 5 6 7 8 9 10 ke tshaba haholo

b. Mofuta o mong oa kankere?

Ha ke tshabe 0 1 2 3 4 5 6 7 8 9 10 ke tshaba haholo

c. Ho khutla hape ha kankere ea thyroid?

Ha ke tshabe 0 1 2 3 4 5 6 7 8 9 10 ke tshaba haholo

d. Ho ata ha kankere mmeleng?

Ha ke tshabe 0 1 2 3 4 5 6 7 8 9 10 ke tshaba haholo

Mat'soenyho kapa longongoreho

14. E be ba leloko la ha oba tetebetse ha kae ke bokulo ba hao?

Ho hang 0 1 2 3 4 5 6 7 8 9 10 haolo

15. E be tshehetso eo o e fumanang ho babang e ea khotsofatsa?

Ho hang 0 1 2 3 4 5 6 7 8 9 10 haolo

16. E kaba kalafo eo o e fumanang e ama likamano tsa hao le batho?

Ho hang 0 1 2 3 4 5 6 7 8 9 10 haolo

17. E be ho kula le kalafo ea hao e ama mosebetsi oa hao?

a. Cheseho ea ho sebetsa?

Ho hang 0 1 2 3 4 5 6 7 8 9 10 haolo

b. Thlahiso mosebetsing?

Ho hang 0 1 2 3 4 5 6 7 8 9 10 haolo

18. E be ho kula le phekolo ea hao li o t'soenya ha kae ka lapeng?

a. Mosebetsing oa hae?

Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

b. Boithabisong?

Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

19. E be khethollo e kae e tlang ka lebaka la bokuli boo le kalafo?

Haho khethollo 0 1 2 3 4 5 6 7 8 9 10 khethollo e ngata haholo

20. O bile le mathata a lichelete hakae ka lebaka la bokuli le kalafo?

Haho bothata 0 1 2 3 4 5 6 7 8 9 10 bothata bo boholo

SEHLOMATHISO SA BOBELI

Leqephe la tlhahisoleseding

1. Sehloho sa patlisiso

Bokang ba bophelo bo bakuli ba nang le kankere/mofetshe o khethehileng oa thyroid.

2. Memo

Lebitso laka ke nyaka Gabriella Lifshitz, ke sebetsa lefapheng la nuclear medicine.

Ke o mamela ho nka karolo patlisisong ena, pele o ka etsa qeto ho bohlokoa ho utloisisa hore ho etsang.

Ka kopo nka nako ho bala le ho botsa ha o lakatsa ho etsa joalo. Ha o sa hlakeloa kapa ha hloka tlhaloso e fetelletseng o ka botsa. O ka nka nako ho nka qeto mahali le ho nka karolo phuputsong ena kapa che. Re leboha ha o balile tsena**.**

3. Bohlokoa ba patlisiso ke bofe?

Patlisiso ena e etselitsoe ho fuphutsa ka liketsahalo tsa Hao ka lebaka la kenkere ea thyroid le liphetoho tseo e li entseng bophelong ba hao ka kakaretso. Patlisiso ena e tlatselletsa ho tse ling tse entsoeng khale le hammamorao, lifuphutsong tse ling likarolong tse ling tsa lefat'se molemong oa papiso.

4. Hobaneng ke khethiloe?

O khethiloe hobane o na le kenkere ea thyroid ebile o fumana kalafo lekaleng la nuclear medicine mona.

5. Na nka nka karolo kapa che?

Ke qeto ea hao ho nka karolo kapa ho se nke karolo patlisisong ena. Ha o lumela ho nka karolo o tla fuoa leqephe la tlhahisoleseding e be o tla bont'sa hore oa lumela. O lumelletsoe ho ikhula patlisisong ena ka nako e feng ka pa efe. Ha oa tlameha ho fana ka lebala.

6. Ho tla etsahala eng ha ke nka karolo?

O tla kopuoa ho tlatsa pampiri potso e tla nka metsotso e leshome ho isa ho e leshome le metso e mehlano. Ditlhaloso tse fumanehang bukeng ya hao ya bophelo letsona litla sebediswa dipatlisisong tsena. Ho nka karola patlisisong ena ha hona le litjeho**.**

7. Ho tlo etsahala eng ha ke sa nke karolo?

Kalafo ea hao ha e tlo ameha **ebile qeto ea hao ha e tlo ana kalani ea hao** moo lekaleng la nuclear medicine.

8. Ho hlokahala eng?

Ka kopo arabela lipotso tsa leqephe leo o le fuoang. Haho tse ling tse hlokuoang ho oena kamanong le patlisisong ena o ka tsoela pele ka bophelo ba hao joaloka mehla.

9. Litla morao tsa ho nka karolo ke lifeng?

Ha rea lebella hore ho kaba le litla morao ha o nka karolo patlisisong ena.

10. Molemo oa ho nka karolo ke ofe?

Leha ho se na melemo e potlakileng e tobileng bohle batla nka karolo lipatlisisong tsena, ho na le tse’po ea hore mosebetsi ona o tla bapala karolo e kholo ho ntlafatsa bo oki ba bakuli ba nang le boloetse ba kenkere ea qoqotho.

11. Na ho nka karolo lipatlisisong tsena e tla lula e le sephiri?

Litaba tsohle tse tla bokelloa ka oena ha ho etsoa lipatlisiso tsena li tla lula e le sephiri. Ha o na tsejoa leho khetholloa lipampering tsohle tse tla tlaleea sephetho sa lipatlisiso. Lintla tse bokelletsoeng li ka abeloa litsi tse ling empa boitsebiso ba hao entse ele sehiri ka sepheo sa ho etsa lipatlisiso tse ling tse amanang.

12. Na ke tla hatisoa ha ke nka karolo?

O ke ke oa hatisoa, pokello ea lintlha e tla etsoa ka mokhoa oa lipotso-potso feela.

13. Ke lintla li feng tse lebelletsoeng ho nna, 'me li tla thusa joang ho fihlela sepheo sa lipatlisiso tsena?

Lipotso tse tla botsoa ke ka maikutlo le boiphihlelo ba hao ho tloha nako eo lipelaelo tsa kenkere li netefalitsoeng. Sepheo sa lipatlisiso keho tseba tsena feela.

14. Ho tla etsahalang ka sephetho sa lipathisiso?

Liphetho tsa lipatlisiso tsena li tlo phatlalatsoa. Boitsebiso ba hao bo ke ke ba hlahisoa lipatlalatsong. Re bolelle ha eba o lakatsa ho bona sephetho sa lipatlisiso tsena, re tla o kenya lenaneng la rona. Sephetho sa lipatlisiso tsena se ka isoa Human Research Ethics Committee (HREC) ha feela ba kopile joalo.

15. Ke mang a hlophisang le ho thusa aka lichelete lipatlisisonng tsena?

Lipatlisiso tsena li etsoa ke lefapha le Nuclear Medicine, University of Witwatersrand, Johannesburg. Ha li hloke lithuso tsa lichelete tse tsoang kantle.

16. Ke mang a lekolang melao ea boits'oaro ea lipatlisiso tse?

Lipatlisiso tsena li amohetsoe ka ha li hlompha melao ea boits'oaro ke lefapha la Human Research Ethics Committee (HREC) (bongaka) University of Witwatersrand, Johannesburg. Etsa bonnete ba

hore o khokahana le Zanele Ndlovu atereseng ya hae ea marangrang eleng (Zanele. Ndlovu@ wits. ac.za) haho kaba le phapanyetsano ea maikutlo tabeng ena.

17. Hotla etsahalang haeba honka karolo hwa hao diphuputsong kapa dipatlisiso tsena dika o bakela hose thabe leho khena ho hoholo?

Re entse bonnete baho fumana Alexa Young, eo eleng setsebi hotsa psychology hore atlo fana ka thlaloso ho wena ka taba ya khatello ea maikutlo le hore na oka tobana jwang le yona, mabapi le diphuputso le ho hlolwa ha hao ho fumana tharollo tabeng ena ka botlalo.

18. Mabistso a batho bao o ka ba atamelang ha o hloka litlhakisetso tse tsoelelletseng

Prof MDTH Vangu, lefapha la Nuclear Medicine Charlotte Maxeke Johannesburg Academic Hospital le University of Witwatersrand, Johannesburg, Afrika Boroa.

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Re leboha ho nka karolo ha hao lipatlisisong tsena.

Sehlomathiso sa boraro

Tumellano e ngotsoeng

SEHLOHO SA THUTO KAPA LIPATLISISO

Boleng ba bophelo ho bakuli ba nang le kankere ea thyroid motsemoholo oa lejoe leputsoa (Johannesburg) ho la Afrika boroa. Maikutlo a bakuli.

Ke balile ebile kea utluisisa t’selimosetso eo ke filoeng.

Ke bile le monyetla oa ho botsa lipotso le ho thuisa likarabo tseo ke li neiloeng.

Ke utloisisa hore ho nka karolo ke bo ikhethelo ba ka, mme nka ikhulela morao ha ke batla mme qeto eo e keke be ea ama tlhokomelo le ho etelea sepetlele nakong e tlang.

Nna……., ke lumela ho nka karolo lipatlisisong tsa boleng ba pophelo ba bakuli ba nang le kankere(mofet’se) Oa thyroid (qoqotho) tse entsoang ke lefapha la Nuclear medicine la Universithi ea Witwatersrand.

APPENDIX 6

Ifomu lokuqala:

Isimo sempilo kwabano mdlavuza we-thyroid

Sawubona. Sinesifiso sokwazi ukuthi umdlavuza we-thyroid ukuphethe kanjani empilweni. Sicela uphendule yonke imibuzo elandelayo, usichazele ukuthi ubuzizwa unjani **emavikini amane (4 weeks)** adlulile.

Ubuwena

1. Ingabe kube yinkinga engakanani lokhu okulandelayo ngenkathi uthola ukuthi unomdlavuza, nangalenkathi welaphelwa umdlavuza we thyroid?

a) Ukukhathala

ayikho inkinga	0	1	2	3	4	5	6	7	8	9	10	**inkinga enkulu**

b) Ukungakuthandisisi ukudla

ayikho inkinga	0	1	2	3	4	5	6	7	8	9	10	**inkinga enkulu**

c) Izinhlungu emzimbeni

ayikho inkinga	0	1	2	3	4	5	6	7	8	9	10	**inkinga enkulu**

d) Ubuthongo

ayikho inkinga	0	1	2	3	4	5	6	7	8	9	10	**inkinga enkulu**

e) Ukuqunjelwa (constipation)

ayikho inkinga	0	1	2	3	4	5	6	7	8	9	10	**inkinga enkulu**

f) Ukungezwani nokubanda nokushisa

ayikho inkinga	0	1	2	3	4	5	6	7	8	9	10	**inkinga enkulu**

g) Isikhumba esomile noshintsho ezinweleni

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

h) Ukushintsha kwezwi (voice)

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

i) Ukusebenzisa izingalo nemilenze

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

41. Uzizwa unjani ngokwempilo (health)?

kubi 0 1 2 3 4 5 6 7 8 9 10

Okumayelana nokomgondo

42. Kunzima kangakanani kuwena ukubhekana/ukumelana nomdlavuzo we-thyroid kanye nokulaphwa kwawo?

akukho nzima 0 1 2 3 4 5 6 7 8 9 10 **kunzima kakhulu**

43. Uzizwa ujabule kangakanani?

angijabulile 0 1 2 3 4 5 6 7 8 9 10 **ngijabulile**

44. Uzizwa kanjani ngendlela okwazi ukulawula (control) ngayo impilo yakho?

angikwazi 0 1 2 3 4 5 6 7 8 9 10 **kuhle**

45. Sinjani isimo sakho sokugxila (concentrate) kulokhu okwenzayo nokukhumbula izinto?

kuyabheda 0 1 2 3 4 5 6 7 8 9 10 **sihle kakhulu**

46. Uzizwa ubaluleke (useful) kangakanani ezimpilweni zabanye abantu?

angibalulekile 0 1 2 3 4 5 6 7 8 9 10 **ngibalulekile**

47. Ingabe umdlavuza we-thyroid noma okusetshenzisiwe ukuze ulashwe kuyishintshile yini indlela obukeka ngayo?

cha 0 1 2 3 4 5 6 7 8 9 10 **kakhulu**

48. Ingabe umdlavuza we-thyroid uyishintshile indlela ozibona ngayo (self-concept)?

cha 0 1 2 3 4 5 6 7 8 9 10 **kakhulu**

49. Ingabe lokhu okulandelayo kukubangela usizi (distress)?

a) Ukutshelwa ukuthi unomdlavuza

cha, alukho usizi 0 1 2 3 4 5 6 7 8 9 10 **usizi olukhulu**

b) Ukuhlinzwa

cha, alukho usizi 0 1 2 3 4 5 6 7 8 9 10 **usizi olukhulu**

c) Isikhathi engaqeda ngaso ukulashwa

cha, alukho usizi 0 1 2 3 4 5 6 7 8 9 10 **usizi olukhulu**

d) Ukulashwa ngemisebe eshisayo (radiation)

cha, alukho usizi 0 1 2 3 4 5 6 7 8 9 10 **usizi olukhulu**

e) Ukuthathwa kwezithombe (scan) e-Nuclear Medicine

cha, alukho usizi 0 1 2 3 4 5 6 7 8 9 10 **usizi olukhulu**

f) Ukuthathwa kwamagazi e-Nuclear Medicine(Thyroid function and Thyroglobulin tests)

cha, alukho usizi 0 1 2 3 4 5 6 7 8 9 10 **usizi olukhulu**

g) Ukuyeka amaphilisi e-thyroid (Eltroxin) ngaphambi kokuba uthole iphilisi eline radiation?

cha, alukho 0 1 2 3 4 5 6 7 8 9 10 **usizi**

usizi **olukhulu**

50. Uzizwa udangele (depressed)?

cha 0 1 2 3 4 5 6 7 8 9 10 **yebo**, **kakhulu**

51. Ukhathazeke (anxiety) kangakanani?

lutho 0 1 2 3 4 5 6 7 8 9 10 **kakhulu**

52. Ukusaba kangakanani lokhu okulandelayo:

a) Ama-test azayo

angisabi 0 1 2 3 4 5 6 7 8 9 10 **ngiyasaba kakhulu**

b) Ukuthola futhi olunye uhlobo lomdlavuza

angisabi 0 1 2 3 4 5 6 7 8 9 10 **ngiyasaba kakhulu**

c) Ukubuya komdlavuza we-thyroid

angisabi 0 1 2 3 4 5 6 7 8 9 10 **ngiyasaba kakhulu**

d) Ukubhebhetheka (metastasis) komdlavuza uye kwamanye amalunga omzimba?

angisabi 0 1 2 3 4 5 6 7 8 9 10 **ngiyasaba kakhulu**

Ukuhlalisana nabanye abantu

53. Kuwuphathe kanjani umndeni wakho ukuzwa ukuthi unomdlavuza we-thyroid?

akubanga inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

54. Ingabe wesekwe (support) ngendlela eyamukelekile futhi oyilindele?

cha 0 1 2 3 4 5 6 7 8 9 10 **yebo, kakhulu**

55. Ingabe ukuza kwakho esibhedlela kubulimazile yini ubudlelwano onabo nalabo ozwana nabo (personal relationships)?

cha 0 1 2 3 4 5 6 7 8 9 10 **yebo, kakhulu**

56. Ingabe ukugula kwakho nokwelashwa kukuphazamise kangakanani emsebenzini?

a) Ugqozi (motivation) lokusebenza?

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

b) Ukuba nemiphumela emihle (productivity) emsebenzini

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

57. Kuyiphazamise kangakanani imisebenzi yasekhaya ukuba nomdlavuza we-thyroid nokulashwa?

a) Imisebenzi yasekhaya

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

b) ukushaywa umoya, uzikhiphe

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

58. Kukuhlukanise (isolation) kangakanani nabantu ukuthola ukuthi unomdlavuza we-thyroid nokulashwa kwawo?

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

59. Ingabe ungene kangakanani ezindlekweni zemali ngenhla yomdlavuza we-thyroid nokulashwa kwawo?

ayikho inkinga 0 1 2 3 4 5 6 7 8 9 10 **inkinga enkulu**

******************************isiphelile imibuzo, siyabonga**************************************

Umthombo wemibuzo:

ISIMO SEMPILO – THYROID

Ifomu lesibili:

Imininingwane ehambelana nokugcwaliswa kwefomu

1. Isihloko socwaningo

Isimo sempilo ebantwini abanesifo somdlavuza we-thyroid e-Johannesburg, South Africa: Ingabe bacabangani laba abanalesi sifo?

2. Isimemo

Igama lami ngingu Dr Gabriella Lifshitz. Ngingomunye wodokotela abasebenza kwi-Department ye-Nuclear Medicine.

Uyamenywa ukuba uphendule imibuzo emibalwa. Ngaphambi kokuthi uphendule imibuzo, kubalulekile ukuthi ube nolwazi lokuthi imibuzo ibuzwelani, nokuthi yini enye okumele uyilindele.

Ngicela uzinike isikhathi sokufunda imininingwane elandelayo ngokukhulu ukucophelela. Uma unemibuzo noma kukhona lapho ungezwa khona kahle, ngicela uxhumane nathi lapha e-Nuclear Medicine.

Awuphoqelekile ukuthi uphendule imibuzo. Thatha isikhathi sakho ngaphambi kokwenza isinqumo.

Ngiyabonga kakhulu ngokufunda lemininingwane.

3. Isiphi isizathu sokwenza lolucwaningo?

Lolucwaningo luzama ukuthola ukuthi umdlavuza we-thyroid uyithinta kanjani impilo yakho.

Imibuzo esiyibuzayo ike yabuzwa ngo dokotela abakwanye amazwe futhi izosinika ithuba lokuthi siqhathanise izimpendulo esizithola kuwena nalezi ezisuka kwamanye amazwe.

4. Ningikhethe kanjani?

Sikukhethile ngoba uke wathola ukuthi unomdlavuza we-thyroid, waphinda futhi walashwa lapha e-Nuclear Medicine.

5. Ngiphoqelekile ukuthi ngiphendule imibuzo?

Awuphoqelekanga neze. Ungazikhethela wena ukuthi uyayiphendula imibuzo noma cha. Uma kwenzeka ufisa ukuphendula imibuzo, leliphepha elinemininingwane lizohlala ngakuwena, kepha sizocela ukuba usayine, uvume ukuthi uzoyiphendula imibuzo. Uma ushintsha umqondo ufisa ukungayiphenduli imibuzo emva kokusayina, ayikho inkinga. Awudingi ngisho ukuthi usichazele isizathu sokushintsha umqondo.

6. Yini engingayilindela uma ngivuma ukubamba iqhaza kulolucwaningo?

Uzocelwa ukuba uphendule imibuzo engathatha imizuzu ewu 10-15 kuphela. Angeke ukhokhe noma uzuze imali.

7. Yini engingayilindela uma nginqaba ukuphendula imibuzo?

Lutho. Ukulashwa kwakho ngeke kuphazamiseke manje nanoma yinini esikhathini esizayo.

8. Yini okulindele ukuba ngiyenze?

Sicela uphendule imibuzo. Akukho okunye esikulindele.

9. Ingabe kukhona okumele ngikuqaphele?

Cha. Ngokubamba iqhaza kulolucwaningo, akukho okubi ongakulindela.

10. Kukhona engizokuzuza?

Akukho okutheni ozokuthola, kepha izimpendulo esizitholayo zizosiza ekutheni sinyuse izinga esiphatha ngazo labo abanomdlavuza we-thyroid, esithemba ukuthi kuzosiza ekunyuseni isimo sempilo sezigulane zethu.

11. Kuzoba yimfihlo na ukubamba kwami iqhaza kulolucwaningo?

Yonke imininingwane izoba yimfihlo. Angeke sibhale igama lakho noma isibongo sakho emafomini. Uma kunesidingo sokuthi izimpendulo zakho ziqhathaniswe nezitholwe abanye abacwaningi, angeke sibatshele igama noma isibongo sakho.

12. Ingabe nizongirekhoda na?

Angeke siqophe lutho. Uzophendula imibuzo ebhaliwe kuphela.

13. Yiluphi uhlobo lwemininingwane enizoyiqoqa? Lubaluleke ngani lolucwaningo?

Ifomu lizoba nemibuzo emayelana nemibono nemizwa yakho seloku wathola ukuthi unomdlavuza we-thyroid. Yilokhu kuphela esifisa ukukwazi.

14. Imiphumela yalolucwaningo izokwenziwani?

Imiphumela sizoyibhala kwenye yamabhuku afundwa abacwaningi. Igama nesibongo sakho ngeke sibhalwe ndawo. Uma unesifiso sokuthola imiphumela yalolucwaningo, sicela usazise. Imiphumela yalolucwaningo kungenzeka siyikhombise iqembu le-Human Research Ethics Committee (HREC).

15. Imali yokwenza ucwaningo izovelaphi?

Ucwaningo luzokwenziwa kwi-Department of Nuclear Medicine, University of the Witwatersrand, Johannesburg. Ayikho imali esiyilindele.

16. Ubani ohlole isimilo salolucwaningo?

Imvume yokwenza lolucwaningo siyithole kwi qembu le-Human Research Ethics Committee ([HREC] (medical), University of the Witwatersrand, Johannesburg.

17. Ubani engingaxhumana naye uma nginemibuzo?

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Siyabonga ngokubamba iqhaza kulolucwaningo.

Ifomu lesithathu:

Imvume yokubamba iqhaza kucwaningo

ISIHLOKO SOCWANINGO

Isimo sempilo ebantwini abanesifo somdlavuza we-thyroid e-Johannesburg, South Africa: Ingabe bacabangani laba abanalesi sifo?

Ngiyifundile futhi ngiyizwile imigomo ebhaliwe.

Ngilitholile ithuba lokubuza imibuzo nelokucabangisisa izimpendulo enginikwe zona.

Ngiyaqonda ukuthi ngibamba iqhaza ngokuzithandela, futhi nginganqaba yinoma yinini. Ukunqaba kwami angeke kuphazamise ukulashwa kwami nendlela engiphatheka ngayo uma ngivakashela esibhedlela ngizothola usizo.

"Mina_____, ngiyavuma ukubamba iqhaza kucwaningo oluhlola isimo sempilo kulabo abanomdlavuza we-thyroid olwenziwa i-Department of Nuclear Medicine, University of the Witwatersrand. Johannesburg.

Ngiyaqonda ukuthi yini elindelekile futhi ngiyafisa ukubamba iqhaza.

Ukusayina kwami ngezansi kukhombisa ukuvuma ukubamba iqhaza.

Isiginesha_____ Usuku_____
Obambe iqhaza

Isiginesha_____ Usuku_____
Ocwaningayo

APPENDIX 7

NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE

Quality of Life - THYROID VERSION

Dear Colleague:

The Quality of Life **(THYROID VERSION)** is a 30-item ordinal scale that measures the Quality of Life (QOL) of a thyroid cancer patient. This tool can be useful in clinical practice as well as for research. This instrument can be administered by mail or in person. The QOL instrument originated in our pain and cancer survivors research and has been adapted for use in thyroid cancer. The tool was developed and tested in a study which evaluated QOL in patients undergoing follow up evaluation for thyroid cancer.

Directions: The patient is asked to read each question and decide if he/she agrees or disagrees with the statement. The patient is then asked to circle a number to indicate the degree to which he/she agrees or disagrees with the statement according to the word anchors on each end of the scale.

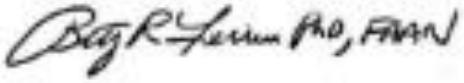
The scoring should be based on a scale of 0 = worst outcome to 10 = best outcome. Several items have reverse anchors and therefore when you code the items you will need to reverse the scores of those items. For example, if a subject circles "3" on such an item, (10-3 = 7) thus you would record a score of 7. The items to be reversed are 1, 3, 10-23, 27. Subscales can be created for analysis purposes by adding all of the items within a subscale and creating a mean score.

You are welcome to use this instrument in your research/clinical practice to gain information about Quality of Life of thyroid patients. You have permission to duplicate this tool.

The QOL instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center (Grant, Padilla, and Ferrell). This thyroid version was adapted from a form created for use in the general population of cancer survivors. A study was conducted in 1995 to evaluate the psychometrics of the cancer survivor instrument as a mail survey to the membership of the National Coalition for Cancer Survivorship. This survey included a Demographic tool, the QOL tool and the FACT-G tool developed by Cella. Psychometric analysis was performed on 686 respondents including measures of reliability and validity. Two measures of reliability included test-retest and internal consistency. In order to perform test-retest reliability, a randomly selected sample of 150 subjects who completed the initial QOL survey were asked to repeat this tool approximately two weeks later. One hundred and ten of the 150 subjects responded for an overall response of 73%. Of the 110 respondents, only those with complete data sets on all variables were used (N=70). The overall QOL-CS tool test re-test reliability was .89 with subscales of physical r = .88, psychological r = .88, social r = .81, spiritual r = .90. The second measure of reliability was computation of internal consistency using Cronbach's alpha coefficient as a measure of agreement

between items and subscales. Analysis revealed an overall r = .93. Subscale alphas ranged from r = .71 for spiritual well being, r = .77 for physical, r = .81 for social, and r = .89 for psychological. Several measures of validity were used to determine the extent to which the instrument measured the concept of QOL in cancer survivors. The first method of content validity was based on a panel of QOL researchers and nurses with expertise in oncology. The second measure used stepwise multiple regression to determine factors most predictive of overall QOL in cancer survivors. Seventeen variables were found to be statistically significant accounting for 91% of the variance in overall QOL. Variables accounting for the greatest percentage were control, aches and pains, uncertainty, satisfaction, future, appearance and fatigue. The fourth measure of validity used Pearson's correlations to estimate the relationships between the subscales of the QOL-CS and the subscales of the established FACT-G tool. There was moderate to strong correlation between associated scales including QOL-CS Physical to FACT Physical (r - .74), QOL-CS Psych to FACT Emotional (r = .65), QOL Social to FACT Social (r = .44). The overall QOL-CS correlation with the FACT-G was .78. Additional measures of validity included correlations of individual items of the QOL-CS tool, factor analysis, and construct validity discriminating known groups of cancer survivors. We have not had a large enough sample of thyroid patients to repeat the psychometric analysis of the version in thyroid patients only. However, the tool is very similar to the cancer survivors version with items 1 h-1, 12, 20, and 21 added to capture the specific QOL concerns of thyroid cancer or thyroid withdrawal.

Good luck with your research!!



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